

**THE USE OF SUPPORT GROUPS IN THE
TREATMENT OF CANCER -
AN INTERACTIONAL APPROACH**

by

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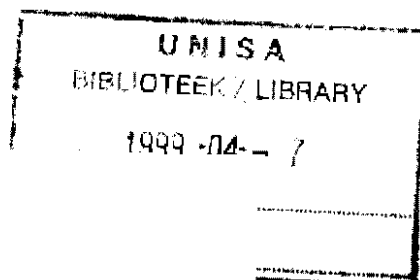
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*This study is dedicated to all cancer patients
and the grace of God.*



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QUOTES

"dread disease demand drastic decisions"

A cancer patient

"why me, or should I say, why not me?"

Another patient

"What is impossible with man, is possible with God."

The Holy Bible: Luke 18:27

"He forgives all my sins, and heals all my diseases."

The Holy Bible: Psalms 103:3

"a problem shared is a problem halved"

The credo of the cancer patient support group

Man's most important problem is not being but living. To live means to be at the crossroads. There are many forces and drives within the self. What direction to take? is a question we face again and again. Human living is being-challenged-in- the-world, not simply being-in-the-world. However, being human is a most precarious condition. The power one unlocks surpasses the power one is, dazzling one. The human's power is explosive. One cannot study the condition of man without being touched by the plight of man. Though biologically intact, man is essentially afflicted with a sense of helplessness, discontent, inferiority and fear. Scratch his skin and you come upon bereavement, affliction, uncertainty and pain. He is prone to suffer mentally and physically. Suppressions are the price he pays for being accepted in society. Adjustment involves assenting to odd auspices, concessions of conscience and inevitable hypocracies. It is, indeed, often a life of quiet desperation.

Who is Man? by A.J. Heschel

But you are not alone. All mankind is travelling with you, for all mankind is on this quest. All humanity is seeking the answer to the confusion, the moral sickness, the spiritual emptiness that oppresses the world. All mankind is crying out for guidance, for comfort, for peace.

Billy Graham

ABSTRACT

This study addresses the importance of studies of human psychoneuroimmunology in understanding the role of psychological factors in cancer. Research trends in psychosocial aspects of cancer are reviewed, exploring the role of distress and the support group as an intervention which potentially reduces distress through enhancing interpersonal relationships, emotional adjustment and communication with health professionals, in these ways helping the patient to cope with the symptoms of treatment. In South Africa, most hospitals which treat cancer patients medically do not simultaneously have support groups for the newly diagnosed patient to join in order to discuss immediate fears and acquire more knowledge about their particular disease.

Following an experimental cancer support group involving patients who had recently undergone a bone marrow transplant (some considerable time after their first cancer diagnosis) in Cape Town's Groote Schuur Hospital, the researcher, as one of the participants in the fortnightly meetings convened to discuss psychosocial issues related to each patient's experience of the cancer and transplant process, transferred the themes, concepts and questions that arose in that scenario, to a cancer clinic in Pretoria where recently diagnosed patients were asked to volunteer to participate in such a group. It was felt that these patients would derive some benefit early in their treatment programme. Psychosocial concerns are left to the individual patient to seek therapy should it be required. Presently, it is reported in the body of knowledge about cancer, that interventions aimed at alleviating the psychosocial distress of cancer patients highlight hypnosis, guided imagery and relaxation therapy. It is contended that a more appropriate intervention for the majority of people with cancer in South Africa would entail a fellow-patient support group meeting on a regular basis.

Key words: Immune function; interactional model; cancer; psychosocial intervention; support group; distress; case studies

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CHAPTER 1

INTRODUCTION

Considerable evidence has accumulated since the 1980s demonstrating psychosocial regulation of immune function. The importance of psychosocial interventions in cancer care to assist patients in dealing with diagnosis and treatment has increased as survival rates have improved with advances in medical care. The goal of an intervention, as described here, is to decrease feelings of alienation by talking with others in a similar situation, to reduce anxiety about the treatments, to assist in clarifying misperceptions and misinformation and to lessen feelings of isolation, helplessness and being neglected by others. Interventions, such as the support group, that are designed to help the person feel less helpless and hopeless have the added benefit of encouraging more responsibility to get well and compliance with medical treatment. Does the evidence indicate the immune system as a link between the mind and the body? Fawzy, Fawzy, Amdt and Pashau (1995), posit that psychological interventions should be used as an integral part of competent, comprehensive medical care and not as an independent treatment modality for cancer.

The human body's reaction to the diagnosis of cancer demands drastic decisions. The medical response is usually concentrated around either surgery or chemotherapy or radiotherapy and in many instances, combinations of the three. The human mind is frequently ignored as a site for simultaneous treatment. However, it is the individual's mind which is an important role player in the patient's response to the distress in that person's psychosocial environment. How the person responds to the stressors in every day life can lead to his or her immune system being weakened and in time compromised to the point where it cannot fulfil its various functions. These include surveillance for any foreign particle that it may react to as a threat to the overall smooth running of the metabolism such as a virus, germ or tumour, and the eradication of this threat by every means at its disposal.

In a healthy system this normally occurs within seconds of the invasion. Chronic psychosocial distress which has accumulated over many years combined with the acute distress of the recent diagnosis requires therapy of mind and body to begin in unison and run parallel to each other if there is to be any lasting cure.

In South Africa, cancer-related decisions concerning an holistic treatment approach need to focus on what type of psychological therapy would best suit the multi-cultured nation. Recent research, mostly in the northern hemisphere, has mainly explored hypnosis, visual imagery and relaxation therapy as interventions for cancer patients. This study proposes that a more appropriate form of intervention would entail the use of fellow-patient support groups.

It is well documented in the literature reported in this study that the recently diagnosed cancer patient struggles to find an opportunity to vent feelings about the disease without seriously frightening family and friends. Patients need to build up knowledge about their particular case, and frequently lines of communication need to be opened between specialist and patient. The emotional support that a group of fellow-patients can give one another can potentially restore sufficient confidence in a person that while he or she is coping with the disease and the treatment, significant relationships can be managed, loneliness overcome and the stigma of the side effects of treatment can be taken in one's stride. Cancer specialists are only recently (since the 1980s) beginning to realise the crucial role of psychoneuroimmunology (PNI) in treatment of the disease. The medical advances in technology may only be effective if the patient's immune system is functioning at optimum. This indicates a multi-disciplinary approach if the patient is to be given the best chance of recovery.

Cancer has reached epidemic proportions in the western world where stress-related illnesses such as high blood pressure and heart disease are prolific. These problems frequently go undiagnosed among the rural black population of southern Africa, although, as soon as people move into towns and cities, they begin to show signs of chronic stress (Pervan et al., 1995). This seems to indicate that the stresses of modern life can have damaging effects on the body. Stress increases output from the adrenal

glands, thereby causing a rise in the levels of adrenaline and cortisone in the body. These hormones can suppress white blood cells in the thymus - the master gland of the immune system, causing it to shrink. This appears to be the mechanism by which stress affects immunity, resulting in an increased vulnerability to infections and invasions from viruses or tumours (Pervan, Cohen & Jaftha, 1995).

Emotional State

The question then arises: Why do some people who are subjected to high levels of stress get sick while others do not? Recent research (Ader, Felten & Cohen, 1991) has shown that anger, and particularly suppressed anger, ranks as the single most powerful suppressor of immune function.

The newly diagnosed cancer patient may therefore benefit from a facility where any pent up anger can be released among people he or she has grown to trust, in surroundings which are conducive to feeling safe, and where information shared is treated confidentially. The patients soon become aware that the role their emotions play in determining their physical health must never be underestimated.

What is Cancer?

Under normal conditions, human body cells divide and grow in an orderly, controlled manner. Cell division and growth are necessary so that the body can perform its functions and repair itself should the need arise.

Cancer cells are different from normal cells because they cannot control their own growth. The reasons for this abnormal growth are thought to be an interaction of hereditary and environmental factors. This means that one can inherit the gene from one's parents leaving the person vulnerable or susceptible to cancer but whether the disease manifests depends on (inter alia) the psychosocial circumstances of that individual, the particular personality (e.g., hardiness) and how these factors may compromise the person's immune function.

A mass of unhealthy cells, or tumour, is considered cancerous when its growth is not controlled. This type of mass usually invades surrounding healthy body tissue and is known as a malignant tumour. When not found early, a malignant tumour can spread or metastasise from its original site to other parts of the body.

All cells, whether they are healthy or cancerous, go through several stages of growth. Together, these stages are called the cell cycle. It is the chemotherapeutic treatment (administered orally or intravenously) which attempts to stop cell growth at some point in the cell cycle by means of the chemical compounds in drugs. The way in which these drugs destroy cancerous cells is unique for each individual depending on the oncologist's treatment plan, the type of cancer and how early the cancer was found.

During a stage in the cell cycle known as mitosis, the cell attempts to divide. At this point, it already contains a miniature supporting structure, a type of cellular skeleton. This skeleton supports the cell, gives the cell its shape and also supports other biological structures within the cell. Just as a person's skeleton must be moveable for one to perform a variety of tasks, so must the cell's skeleton be moveable. Chemotherapy "paralyzes" this support structure inside the cell. The cell is then unable to perform the functions necessary for growth or reproduction, so it is unable to reproduce and eventually dies.

The Researcher's Own Point of Reference

"Who can I talk to, who will listen?", "the doctor never has time", "if I tell him about this new pain, it only will make things worse".

The researcher was diagnosed with cancer (lymphoma) in Cape Town in 1992. There were many questions that needed to be answered about the disease itself: what to expect from the treatment and what the chances of recovery were, yet fearing the responses and seeing the medical staff so busy with other patients, there was no communication channel between patient and doctor. Chemotherapy and radiation treatment went by, then remission, then relapse and more powerful treatment, then

remission again. Still, vital questions were not being answered as increasing psychological problems needed attention. Communication about things that really mattered seemed frozen from fear. Then came the bone marrow transplant in August 1995 where the researcher was informed by the specialist that there was a 50 percent chance of recovery. In October that year, at long last, fellow-patients formed a support group that met on a fortnightly basis. The group talked about physical symptoms at first, comparing notes, then when it gradually felt safe and confidential in an atmosphere of mutual trust, it aired real concerns. Some stuff went back decades. The haematology clinic's social worker facilitated the group to ensure the smooth running of the meetings.

In October 1996: "come for check-ups once a year please". The magic words had come from the specialist. It seemed strange that the support group had not started nearer the initial diagnosis. After being permitted to continue studying away from Cape Town and being accepted into a directed, two year Masters degree programme at UNISA in Pretoria, the researcher hypothesised that forming support groups for recently diagnosed cancer patients would fill a gap in the knowledge concerning cancer patients' needs in South Africa.

This research is focused on attempting to form a support group in a Pretoria cancer clinic for recently-diagnosed cancer patients. This mind-body treatment of cancer is a recent phenomenon at hospitals in South Africa. Most oncology wards have a social worker but it is up to the patient to make an appointment and the idea of speaking to someone new about the disease seems frightening just after diagnosis as frequently answers are being sought of a medical nature: why are my toenails falling off?, how can I stop this terrible nausea?, what has happened to my memory, it used to be so reliable?

Cancer: An Historical Overview

Over the centuries, theories about cancer were developed in an attempt to explain the nature of the disease to physicians. These explanations were restricted to

contemporary philosophical, theological and scientific knowledge and throughout the centuries, cancer sufferers have been the subject of almost all conceivable form of experimentation (Pervan, et al., 1995, pp. 3-7).

Ancient Egypt

In ancient Egypt the practices of medicine and religion were so intermingled that all the deities were associated with some form of health or illness. Isis was revered as the prominent surgeon and many important Egyptian papyri (one, notably the Ebers papyrus of 1600 BC) indicate that cancer was obviously known to man in that era. Distinctions were made between the benign and malignant tumours, and comment is made that surface tumours may be successfully removed surgically(Pervan et al., 1995, p. 3).

Classical Greece

Between 500 and 400 BC Greece's "Golden Age" was beginning in Athens, and it continued to 322 BC when Alexander the Great conquered Egypt. This conquest resulted in the blending of Egyptian and Greek theories on medicine and disease.

Plato's thoughts on medicine emphasised the immaterial, the soul, the mind, ideas, qualities and relationships. Aristotle expanded on these concepts to include Form (immaterial) and Matter (material) and explained most physiological processes according to Plato's concepts of the four causes: the formal cause, the material cause, the efficient cause and the final cause (Pervan et al., 1995, p. 4). Hippocrates who lived between 460 and 370 BC is, however, considered the father of medicine. He is also the father of oncology, the science of the study of cancer. Hippocrates was the first person to use the term carcinoma (the cancerous development) which is derived from the Greek word KARKINOS, meaning crab.

The next major cancer milestone was the medical Renaissance of early 1600. Aristotelian rationalism with its meta-physical foundation was replaced by a new

empiricism with an experimental base. Quantitative research had completely replaced the mind-body approach to cancer. However, it was not until the 1950s that treatment began to regard both aspects of the disease as equally important if the patient was to be given a fuller chance of recovery(Pervan et al., 1995).

An African Perspective on Disease

Cancer, which is often accompanied by altered body image, loss and death, is a devastating experience for any family, irrespective of colour, creed or race, and so arouses great anxiety and fear in the patient, the family and significant others. People confronted with the diagnosis of cancer always ask "why". Medical science answers the question "how", but not "why". It is to find this latter answer that people consult sangomas, prophets, spirit mediums, fortune tellers etcetera.

Colonialism, apartheid, urbanisation and modern development have arrested some of the African's religious principles. African black people (Hammond-Tooke, 1974) have a culture and way of living which expresses their religious beliefs. This cultural way of living is guided by two important elements, namely God (uQamata) and the ancestors (izinyanya) (Shosha, in Pervan et al., 1995 pp. 311-318).

Africans had no written religious literature but believed that their ancestors were keeping in touch with uQamata, the creator, who was invisible. For black people, the basic principles of good living are:

To obey God's commands is to obey the ancestors' commands.

To be loyal to the ancestors.

Good communication.

To show respect to the ancestors.

Communication is the key to the best way of living as it ensures a good relationship between the living family members and their ancestors. Once there is communication breakdown there is no hope for good healthy living (Sasha, in Pervan et al., 1995, p.

311). Western-style health care normally starts and ends with the body of the sick person. Sick people become isolated in the strange, sterile hospital environment, with very little communication and few visitors or none at all if they come from far away. The hospital routine alone is sufficient to drive them "insane".

In contrast, traditional healing takes place in the familiar home environment of the patient or in the home of the healer. The family is actively involved in the process of healing from diagnosis to the treatment stage. The ancestors are also invited to join in and help with the healing process. The person, therefore, gains strength from the warmth of the environment and support from family and friends (Sasha, in Pervan et al., 1995, p. 312).

Any major illness leaves the entire family devastated and threatened. As the cancer patient shows physical symptoms (e.g. from the treatment and from the cancer itself) fear and anxiety will grip the entire family and community, leaving everyone feeling threatened. The illness is believed to be caused by the active and purposeful intervention of a deity, ghost, ancestor, evil spirit or human being (i.e. witch or sorcerer). The family will take action to try to deal with the disease. Grandparents are traditionally active with fumigation and the use of aromatic plants to drive out evil spirits, thereby appeasing the ancestors. This is done before outside help is sought (Shosha, in Pervan et al., 1995, p. 315).

In conclusion, the fellow -patient support group may be a useful bridging process for multi-cultural cancer patients. Potentially, such patients can communicate freely with others in a similar predicament and in so doing acquire strength in a warm, safe and confidential environment. Health care professionals involved with cancer patients and their families need an in-depth understanding of each patient's cultural and religious beliefs.

Overview of the Study

The process whereby one caring and empathic person listens to another's problems and the feelings linked to these problems is generally accepted as being therapeutic and cathartic (Miller, 1996, p. 109). The more the caregiver (in this study, the group facilitator and the person's fellow patients) can offer empathy and support to the cancer patient, the greater the potential that the interactive process will bring about significant stress reduction.

This study attempts to explore the use of support groups in an oncology treatment clinic as an aid to alleviating the distress that a recently diagnosed cancer patient experiences. It is hypothesised that, if successful, such an intervention will leave the patient in a frame of mind where he or she is better able to cope with the initial and subsequent crises and the negative feelings surrounding them. This informal form of counselling by the stake-holders serves to potentially restore the communication channels between doctor, patient and other significant relationships in the patient's life. Moreover, each person's immune system may gradually be strengthened in the task of coping with the effects of psychosocial distress, thereby enhancing the effectiveness of managing the cancer and its concomitant treatment.

CHAPTER 2

THE THEORETICAL FRAMEWORK

To understand the place of psychosocial interventions towards a biological condition such as cancer, it is useful to highlight two aspects of sickness: disease and illness. Kleinman (1986) refers to disease as a malfunctioning of biological and/or psychological processes and the way the illness experience is re-interpreted by medical practitioners in terms of their theoretical models and clinical expertise. The social production of disease refers to reformulations of disease as malfunctioning and maladaptive in biological systems. Illness, however, refers to the psychosocial experience and meaning of perceived disease. Illness includes personal and social responses to a primary malfunctioning (disease) in the individual's physiological or psychological status, or both. Moreover, illness involves processes of attention, perception, affective response, cognition and valuation directed at the disease and its manifestations (e.g. symptoms being labelled, role impairment etc.). Also included in the concept of illness are communication and interpersonal interaction, particularly within the context of the family and social network (Kleinman, 1986, p.146). From this perspective, illness is the shaping of disease into behaviour and experience; for example, cancer the illness is created by personal, social and cultural reactions to cancer the disease. Illness indicates the way the person and his or her family and peers perceive the symptoms, their concomitant labelling of them, their experience of them and how they articulate that illness experience through pathways of distress and help-seeking.

The construction of illness from disease is one of the main functions of health care systems (a coping function) and the first stage of healing (Kleinman, 1986). This idea effectively denotes illness as containing responses to disease which attempt to provide it with a meaningful form, explanation and control. Therefore, it may be said that illness is part of care. It is both a psychosocial and cultural adaptive response.

Disease affects single individuals even when it attacks a population (Kleinman, 1980).

Illness, on the other hand, most frequently affects the patient's family, social network and at times, an entire community (e.g. an African perspective previously mentioned). In an interactional model, the health care systems which pertain to modern cancer treatment from a biopsychosocial perspective, view the realities of disease and illness as representing relationships in the patient's life-world.

When one falls sick, one first experiences illness. That is, one perceives, labels, communicates, interprets and copes with symptoms while in interaction with family, friends and colleagues. Personal, interactional and cultural norms guide this lived experience, which implies that shared cultural beliefs (about the body, the self, specific symptoms and illness generally), constraints in one's concrete social situation and aspects of the individual (personality, coping style, prior experience, etc.) orient one how to act when ill, how to communicate distress, how to manage the life problems illness creates and how to negotiate this social reality and interpret its meaning intersubjectively (Kornblum & Smith, 1994).

Kleinman (1986) maintains, in reference to health care systems, that the most important concept for cross-cultural studies of medicine is an appreciation that in all societies, health care activities are more or less interrelated. This implies that they be studied in an holistic manner as socially organised responses to disease that constitute a special cultural system: the health care system.

Patients and healers are basic components of such systems and are, therefore, embedded in special arrangements of cultural meanings and social relationships. In fact, they cannot be understood apart from this context. Moreover, illness and healing are part of the system of health care. Within that system, they are expressed as culturally-constituted experiences and activities, respectively. In the context of culture, the study of patients and healers, and illness and healing must, therefore, start with an analysis of health care systems.

In order to fully comprehend the specific characteristics of all the forces or systems in constant, bi-directional interaction within the cancer patient's life world,

consideration of the person's family, disease and the particular health care processes is necessary. No illness exists in a vacuum. Families(as support mechanisms) and persons as systems have semi-permeable, psychosocial boundaries that medical staff are required to cross all the time after an initial diagnosis. The patient coming to a hospital or cancer clinic is crossing the boundary of the health care system(Henao & Grose, 1985, p. 47).

Another important facet of the reciprocal interaction among systems in the cancer patient's life, is that of a dynamic equilibrium. Physical disease and other changes in life circumstances serve to momentarily disturb a person's equilibrium. The symptoms, meanwhile, have a re-balancing effect in that the system adapts to a new set of conditions. Hence, the symptom(e.g., a noticeable growth on the person's skin) is part of the adjustment (Steinglass, 1992, p. 20).

Cancer is a disease with manifestations at all levels of interaction, in which changes at one level (e.g., a low white cell blood count on the day a patient is due to receive chemotherapy would lead to a postponement of that treatment) are associated with shifts at other levels, particularly (in this example) the psychological and family/social interaction (Henao & Grose, 1985). These are not uni-directional changes because emotions (e.g anxiety about the low blood count: "what now?" "how?" and "why?") have physical effects as well through the complex, feedback interaction among systems.

Family factors in health care may be addressed from four different perspectives(Henao & Grose, 1985, p. 46). Firstly, they may be resources for individuals coping with cancer. Secondly, they may be contributors to the development of the cancer. Thirdly, they may influence the relationships with health care personnel and particular forms of treatment such as when fanning or quelling the fear surrounding the claustrophobic experience of a magnetic resonance imagery scan or encouraging the patient to refuse chemotherapy because it is "poisonous". Finally, they may determine the course of the specific cancer. Allen (1983), in considering the psychosocial factors in the cancer patient, maintains that when the patient requests information about his illness, the oncologist should give an honest, complete and accurate presentation of all the facts to both the patient and the family. Family members should be included in the

discussion so as to fulfil their important role as members of the treatment team. In the light of this, an interactional model is proposed as best depicting all the factors in interaction in a cancer patient's life world.

A Christian Experience with Cancer

In the haematology isolation unit at Groote Schuur hospital in Cape Town, a patient is prepared for a bone marrow transplant with large doses of chemotherapy and whole body radiation. While the researcher was undergoing this procedure in July and August 1995, a priest (Fr Sean) visited this patient on the same day he had been informed by one of the specialists that he had a 50 percent chance of recovery.

As it was an isolation unit, the priest had to remove his normal attire to replace it with protective clothing to prevent contamination. He told the researcher that at that moment a personal relationship with Jesus Christ the Son of God was more important than worrying about the outcome of the operation. The researcher, then aged 40, was confused by this suggestion: "why now?" (he thought). The priest then asked him to accept Jesus as his personal Saviour and friend. In fighting for survival the researcher was prepared to do anything. The guilt of having such a relationship with the Lord while still at school and allowing it to lapse still remained. Before anything else he felt the need to ask for forgiveness for falling away from the Faith and for all the other sins committed since then. He then prayed with the priest that Jesus would undertake in the circumstances at that time. The priest left after a few minutes. He returned on the day before the transplant (2nd August) and on this occasion it appeared that he already knew the relationship with Jesus had begun (again). In his protective wear once more he prayed that it would grow stronger through prayer and Scripture readings. This left the researcher with more hope that he would be able to recover and grow with the Lord. The uncertainty of the following day was replaced with a feeling of peace and a sense that it would endure-no matter the outcome of the transplant. Again the priest left after a few minutes.

The bone marrow transplant was a success and there was no rejection. The

chemotherapy to the brain had to continue but on a reduced scale and only for three months intrathecally (via the spinal chord). The magnetic resonance imagery (MRI) scan in October 1996 showed no traces of the three brain tumours. When the researcher was shown the pre- and post-transplant scans and shown how to read them it was evident that something miraculous had happened. The experience left the researcher feeling extremely humble and grateful to the Lord for His mercy. Furthermore, the prospect of sharing the experience with fellow patients at a future date became very exciting in that they may also be introduced to the Saviour. When the oncologist at Groote Schuur said that blood tests would only be necessary once a year, the researcher immediately applied to UNISA in Pretoria for an opportunity to join their directed research masters degree over two years. When he was accepted he moved to Pretoria and on the next day (a Sunday) attended a church service where, afterwards, he was introduced by his landlady to Dr Georges de Muelenaere who after a discussion, invited him to conduct the research into support group effectiveness for cancer patients at his clinic. The Lord was very busy and very powerful.

An Interactional Model

Marsella (in O'Connor & Lubin, 1984, pp. 232-250) postulates a general interactional model which is appropriate for studying stress and cancer (see Figure 1). The person is viewed as a product of both internal (i.e., biological and psychological) and external (i.e., environmental and cultural) forces or systems. This product is equal to the sum of all these forces in ongoing, reciprocal interaction plus the emergent quality which results from all the particular (in the person's life) forces acting together. Within this context, no force operates independently of other forces, but rather must constantly be in interaction with other forces across time.

Another element of this model are the feedback mechanisms that link the person-situation components. Within this framework a disease (such as cancer) emerges from the ongoing adaptational changes of the person-situation interactions. The changes

which occur at internal and external levels lead to changes in the subjective and objective aspects of the person and the situation.

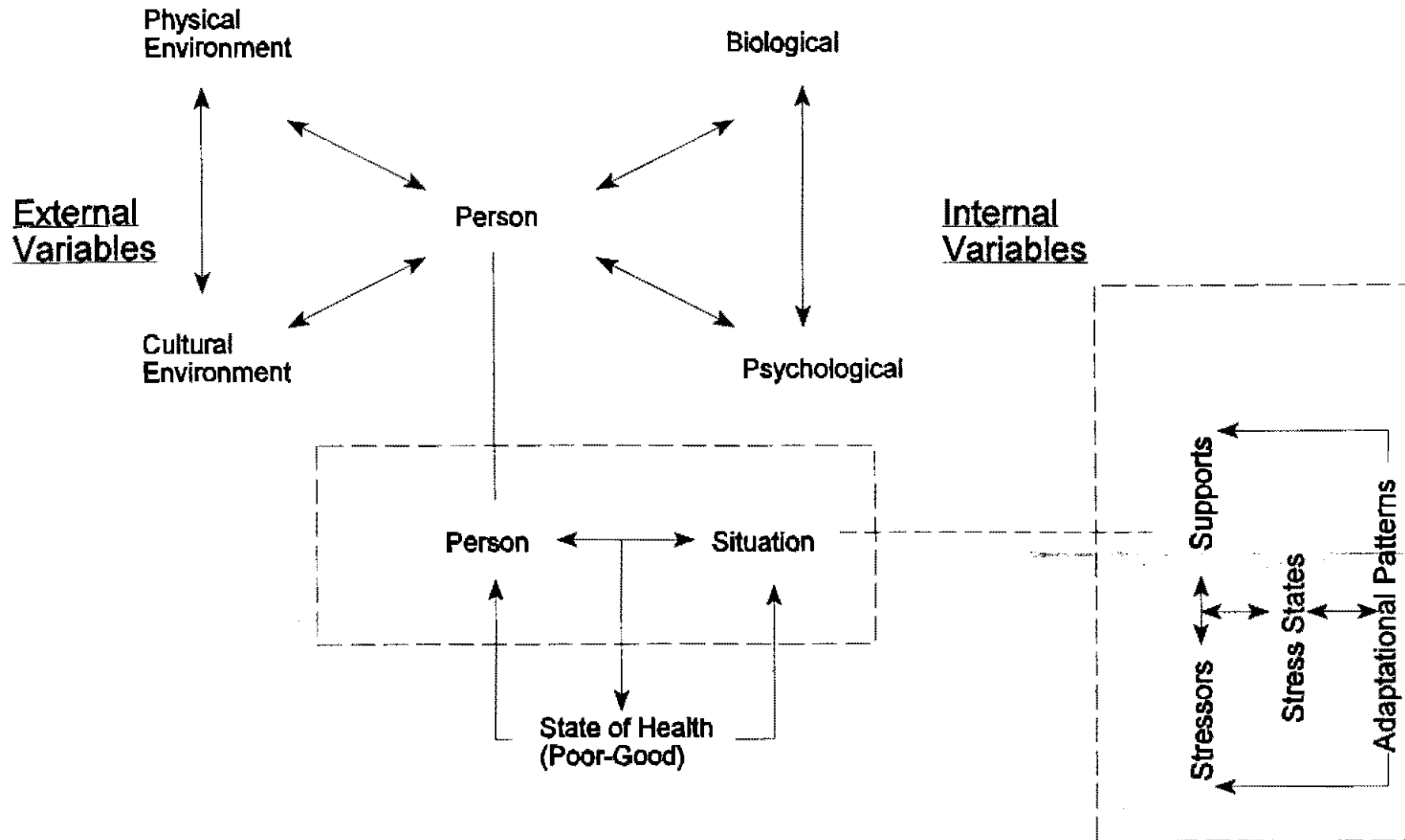
The human body, within its organismic-situational interactions, can be viewed as a coping response system that functions at biological, psychological and sociological levels. The situation is represented as a source of stressors. The simultaneous interaction of stressors and coping (or support systems) and malignancy, in this instance, then lead to interactional patterns the person develops. Cancer is regarded as adaptational in that it represents response patterns to psychological and physiological stress states.

When an intervention, such as a support group, is introduced to reduce the level of psychosocial distress in a cancer patient, this can be regarded as a crucial part of the simultaneous mind-body treatment as the person's immune system is potentially positively effected which in turn effects the reaction to treatment.

Aim and Motivation

The aim of this study is to test whether psychosocial support can reduce Unresolved Psychosocial Distress (UPD) in a newly diagnosed cancer patient.

Figure 1: Human stress and cancer: An interactional model



Currently, in South Africa, only certain hospitals can contend with the increasing amount of people needing treatment for cancer. Patients frequently travel long distances to keep their appointments which results in having to reduce the extra expenses (such as an individualised therapy programme) as much as possible; this applies to hospital patients and those on a medical aid. South African hospitals do not make use of post-diagnostic support groups where fellow patients can, amongst other things in a structured programme, share common problems and gradually begin to empower themselves. Potentially, such a support group would evoke a positive immune system response to strengthen the metabolism's reaction to not only the treatment of cancer but also the cancer itself.

This project intends to fill the gap that exists in psychoimmunological research in South Africa (concerning psychosocial interventions in a hospital setting), thereby presenting a more complete approach to the mind-body treatment of the cancer patient.

CHAPTER 3

LITERATURE SURVEY AND CLARIFYING THE TERMINOLOGY

The importance of cancer-treatment issues has increased markedly over the past decade. The emphasis has been placed on psychoneuroimmunology (PNI) which is the study of the interrelations between the central nervous system and the immune system. The term interrelations is used because the assumptions are that the relations are bi-directional. Ader, Felten and Cohen (1991) link the factors in psyche-brain-immune functioning (such as stress, depression, social support and repression/denial), however, it is recently documented psycho-immunology (Lewis, O'Sullivan & Barracough, 1994) that deals with the specific, direct interaction between the psyche and the immune system and is the more appropriate science whenever diseases are thought to be distress related.

In its broadest definition, psychoimmunology encompasses virtually anything within an organism, since most immune cells have access to all organs and body tissue, including the central nervous system. This in turn influences the peripheral nervous system which then influences the functioning of bodily organs. One of the aims of psychoimmunology (Lewis et al., 1994, p.3) is to study how the fight against, or prevention of cancer could be pursued and it is in this context that the present project will be undertaken.

The immune system in humans is a complex surveillance apparatus that functions to protect the body from damage by invading organisms - bacteria, viruses, fungi and parasites - called antigens. The system consists mainly of T-lymphocytes and natural killer cells which occur in circulating peripheral blood between organs of the immune system such as lymph nodes and bone marrow.

Stressful life events alter immunity and hence susceptibility to immune system-mediated disease. Lewis et al. (1994) examine stressors as mediators of immune

changes. Stress research is regarded as an area of psychoimmunology with a proven scientific basis and a person's stress mechanisms central to immunity and human behaviour. Stress is defined as the response of a system to environmental influences which then push the system's function off balance. A stressor is defined as a stimulus that evokes an abnormal physiological response. In the case of human organisms the stressor need not be external to the system, but may originate from past material stored in the organism such as unresolved (i.e., unmanaged or untreated) distress.

Cooper and Watson (1991, p. 11) examine areas of overlap in psychoneuroimmunology so as to elucidate the potential of PNI in cancer research. Psychosocial factors such as emotions, unresolved distress, social support, coping modes and particular personality traits influence the course of cancer, especially after initial diagnosis, when all the forces of mind and body must collaborate for treatment to be effective.

Do Psychosocial Factors Influence Immunity and Cancer?

Bovbjerg (1991, pp. 417-425) assesses the role of psychosocial factors in cancer etiology, progression and treatment response and reveals three general categories of psychosocial variables associated with cancer: a history of psychic distress, social support and personality.

Miller (1996) calls for research to examine the relationship between psychosocial variables, immune functioning and cancer if the patient is to be treated in his or her entirety. Lewis et al. (1994) examine stressors as mediators of immune changes.

Cohen and Herbert (1996, pp. 114-135) investigate immune system-mediated disease and contend that when demands imposed by events exceed individuals' abilities to cope, a psychological stress response composed of negative cognitive and emotional states is elicited. Lewis et al. (1994) postulate that it is chronic stress which leads to fatigue of the stress-responding system, thereby leading to permanent impairment and to the acquisition of maladaptive stress-response patterns.

Since psychoimmunological mechanisms are important for stress, it is logical that they will also be important for a disease such as cancer. Illness is, in fact, a particular state of the organism adapting to environmental demands and is therefore a function of the human organism and the environment. The body responds to medical disease as a whole and the end result of the now damaged-organism interaction depends on the level of function of the organism (human) as well as on the type of invasion (say, the carcinogen in cancer).

Interpersonal Relationships

Cohen and Herbert (1996, p.124) review evidence implicating interpersonal relationships in the maintenance of healthy immune functioning. Recent studies of loneliness, separation and divorce, perceptions of support and disclosure of traumatic events elucidate the impact of interpersonal relationships on immunity and immune system-mediated illness. Poorer marital relations are associated with poorer health, and relatedly, perceived availability of social support has been shown to effect the immune function; the simple availability of emotional support in the form of someone to talk to about problems was a crucial variable, in that it helped the patient feel more relaxed and able to cope with any fear and anxiety (Cohen,1985).

More recent literature reported in Cohen and Herbert (1996, p. 126) has examined the potential health benefits associated with peoples' disclosure of traumatic events. These therapeutic interventions included stress management training and education about cancer and focused attention on future research adequately defining the social resources to be provided, the nature of the population, the source of the support, the strategies for structuring group interaction and the duration of the intervention.

Personality

Relations between personality characteristics and immune function have received little scientific attention. Miller (1996) limits this focus to repression and/or denial because it has been studied in relation to both immune function and to immune system-

mediated disease (AIDS and cancer).

Repression/denial represents a coping strategy against threatening information and is characterised by denial or minimisation of distress and negative emotions. Repressors react to stressful stimuli with higher measurable arousal than persons actually reporting high anxiety or distress.

A major focus of research in the field of personality (Miller 1996) has been the role of personality variables in moderating the relationships between stress and psychological and/or physical illness but not specifically the immune function. The studies focus on personality characteristics which may potentially differentiate people who deteriorate physically and/or psychologically under stress from those who appear to be able to tolerate high levels of stress without faltering. Psychological hardiness, as a stress buffer, is defined as a composite of the constructs commitment, challenge and control, and regarded as a psychometric and predictive 'instrument' for future research (Miller, 1996, pp. 161-178).

Psychological Factors that Influence Immune System-mediated Disease

Invasion of the body by a disease-causing agent is not sufficient cause for disease. Disease occurs when the body's defences are compromised including being unable to recognise the foreign material. This is why psychological variables that influence immunity have the potential to influence the onset and progression of immune system-mediated diseases such as cancer. Whether psychologically induced changes in immunity are of the strength or type that would alter the ability of the body to fight disease, depends on the individual.

Cancer

Cohen and Herbert (1996) define cancer as comprising a large and heterogeneous group of diseases characterised by the uncontrolled proliferation of cells. Because of the crucial roles that the immune system plays in tumour surveillance and in preventing

the progression and spread of tumours, psychological factors associated with immunity are considered powerful contributors to cancer onset and progression.

Cooper and Watson (1991, pp. 147-170) examine recent work on the role of psychosocial factors in cancer risk and survival and categorise these factors: Firstly, a personality characterised by suppression of emotional reactions, especially anger, and by the inability to have satisfactory relationships and also by conformity/compliance. Secondly, supported by Lewis et al. (1994), the experience of depressive symptoms, feelings of hopelessness/helplessness and bereavement are consistently associated with cancer risk. Thirdly, the experience of distress, or the chance to buffer stress by improving coping or by the provision of social support has a significant influence on cancer risk or survival.

Under the heading "Psychological factors and the immune system" Cooper and Watson (1991, p. 47) discuss the immune responses that are affected by psychological factors and have been shown to be associated with cancer. In this regard, suppressed anger or an unhealthy habit such as smoking in operation over a long period, has been found to reduce the effectiveness of t-lymphocytes and natural killer cells (major components of human immune systems and a measure of PNI response to distress), which leaves the person susceptible to cancer invasion.

The study of psychoneuroimmunology in relation to cancer patients has highlighted different approaches: firstly, the study of the association between psychosocial factors, cancer outcome and measures of immune function. Secondly, an investigation of the psychological and immunological responses to stressful, cancer-related issues and of the impact of interventions aimed at reducing distress and improving coping and adjustment. These are recent developments and studies tend to overlap into the approaches, but the common factor for future research is a combination of both qualitative (e.g., support group research) and quantitative (e.g., experimental design research where patients are randomly selected and randomly assigned to treatment and control groups) methods if the patient is to receive full advantage of available knowledge on the biopsychosocial treatment of cancer.

With regard to the quantitative approach, Fawzy et al. (in Helgeson & Cohen, 1996, p. 140), in a six week research programme, assigned cancer patients to experimental and control groups. The experimental group activities included health education, enhancement of problem-solving skills, stress management (e.g., relaxation techniques) and psychological support from fellow patients. Patient distress, as measured by self-report feedback (a qualitative measure) and an appropriate pre- post programme life events scale, was reduced in the experimental group at the end of the intervention and to a greater extent at six-month follow up. These results are regarded as highly interesting but needing replication and extension.

Studies of the impact of psychosocial factors on cancer have become more complex with the inclusion of immune responses as mediating factors. Moreover, several methodological problems such as control for interfering factors (e.g., insomnia) necessitate that research simultaneously assess behaviour, immunity and illness. These confounding variables, to a large degree, can be monitored by simultaneous qualitative and quantitative techniques.

Psychosocial Interventions and Immune Function

Since cancer is an individualistic illness and each person copes with their unique diagnosis differently, the most appropriate form of recording personal information would be one which permitted each patient freedom of expression to capture the richness of how that person perceives each situation.

However, several common themes have emerged from open-ended analyses of cancer patients' thinking. Cooper and Watson (1991) focus on the most outstanding of these: (a) fear of recurrence; (b) the extent to which patients feel stigmatised as the result of having cancer; (c) the manner in which this sense of stigma is frequently related to the patient's contacts with the larger social world (e.g., healthcare professionals, employers, friends, family); (d) the patient's difficult task of developing a voice with health care professionals in institutions; and (e) the dramatic and traumatic changes a cancer diagnosis makes to a person's lifestyle; long-term as well as short-

term.

To interpret these psychosocial problems as a product of negative or irrational thinking fails to place the experience of chronic illness in the context of the social and historical referents of the patient as well as the interactional demands arising from the biological and psychological realities of disease and illness, and the institutional context of medicine. The researcher of any psychosocial intervention must thus be aware of the patient's need for continual readjustment of identity in the face of the chronic illness.

Patients who live with cancer find themselves in an ongoing interaction of dynamic psychosocial events, including bodily changes, relationship stressors, time management constraints and frequently institutional events. For patients with cancer it is vital that they renegotiate their identity status with family, friends, co-workers and medical personnel. Patients frequently report that they "feel like a different person" as a result of their cancer experiences, and have a great need to communicate about their identity with people who know what they are experiencing (Cooper & Watson, 1991, p. 176).

It is never possible to renegotiate one's identity alone. Rebuilding one's identity necessarily involves the larger social world. The experience of cancer introduces into the patient's world new constraints and plans-of-action which also effect those who care for them physically or emotionally. Interventions with cancer patients become effective only if the focus remains on the person and the illness and not solely the disease.

Cooper and Watson (1991) in examining recent studies of psychosocial interventions and immune function highlight the interaction of a person's diagnosis of cancer with changes in one's psychological well being as well as the immediate social environment. Depending on the nature of the individual and the precise circumstances, such a diagnosis can be accompanied by feelings of hopelessness, despair and loss of control over one's destiny. In addition, the mere diagnosis can be accompanied by social rejection. This contributes to the victim's feeling of hopelessness which may, in turn, coincide with a number of neuroimmunology changes leading to the systems being

compromised. The potential role of social support in altering the balance between health and disease is a variable common to all studies designed to evaluate the effects of psychosocial factors on the immune system. The social support may be derived from interpersonal relationships in various environments or from interactions with fellow patients, the researcher or therapist.

Another variable is the importance of the subject's belief that the psychosocial intervention will be successful (Cooper & Watson, 1991, p. 180). In addition, by actively participating in the intervention the subjects will assume a measure of responsibility for their health. This tends to offset the feelings of helplessness and loss of hope which are important factors in research about psychoimmunology and its relevance to cancer.

Interventions

The systematic use of psychological approaches in the treatment of cancer and cancer-related problems has been practised since the late 1970s. These interventions include guided imagery, making use of relaxation techniques, hypnosis and prayer.

Watson (1991) refers to the possible adverse consequences that research has revealed where these interventions were used. An example would be the detrimental side effects after hypnosis of having to suddenly, consciously cope with previously denied traumatic events in addition to the trauma of the cancer and its particular treatment. It is worthwhile to bear in mind that more recent studies have highlighted the recently-diagnosed cancer patient's reluctance to talk about his/her disease with anyone in the hospital environment including the oncologist and other health professionals for fear that they will not understand what the person is going through, so verbalisation of problems becomes traumatic in the patient's not knowing how to put problems into words (Watson, 1991).

As far as the use of relaxation and guided imagery-based interventions are concerned, the belief that by changing one's mental outlook or behaviour one can stop

or slow down the progression of cancer, can incorporate the view that the disease was somehow initiated as a consequence of a maladaptive psychological state or behaviour which then leads to guilt. In some instances, the guilt may be internalised should the patient believe that he or she did something to precipitate the onset of the disease. In other instances, the resentment has been directed at family members, friends or colleagues who may be perceived to be responsible for triggering the emotional upheaval (Ader, et al., 1991, p. 58).

However, one's belief in the efficiency of an intervention is not the only variable in psycho-social interventions. Relaxation on its own can have therapeutic effects through the interaction of hormonal factors in the brain being able to reduce anxiety and stress levels which in turn affects the immune system's responses to the cancer. When attempting to understand the mechanism via which psychosocial interventions might modulate immunity, it is important to realise that the intervention strategy and how it is carried out may in turn be a reflection of the immunological status of the individual. For example, a cancer patient who is severely depressed at the diagnosis stage, would require medical intervention (or hypnosis) for the depression before the possibility of joining a support group could be considered by the treatment team (Ader et al., 1991).

A more recent intervention strategy is the use of support groups in the treatment of cancer patients.

Group Therapies: What is a Support Group?

In this research, 'support group' is defined as between two and twelve cancer patients meeting on a regular basis. Topics of discussion may initially focus on the physical (such as the side effects of the medical treatment of cancer), and gradually feelings are evoked which potentially bring unresolved psychosocial issues to the person's conscious level. Cooper and Watson (1991, p. 179) propose five objectives for such a group of cancer patients; namely, support in any way possible, sharing feelings, developing coping skills, gathering information for self-education and considering existential issues. In South Africa, this form of psychosocial intervention with newly

diagnosed cancer patients, facilitated by a cancer survivor, is rare.

Why do patients join support groups? Cooper and Watson (1991, p. 180) report that although most patients claim high levels of support after diagnosis, some patients experience isolated instances of rejection or do not receive the type of support they, personally, would find helpful. It has been found in a recent study that working in the group fosters an optimistic attitude towards oneself and a fighting spirit towards the progression of the disease.

Also, support group attenders were more likely than non-attenders to be middle-class female, to report having more problems, and to access support services of all kinds. Negative experience with the medical community was a predictor of joining a group, suggesting that patients were using the group to vent feelings which were the result of problems experienced elsewhere in the medical system. Finally, the research found that attenders showed no greater psychosocial distress than non-attenders (Cooper & Watson, 1991, p. 183). At the very least, this research suggests that cancer patients willing to take part in a support group are not necessarily better or worse off than other patients, but may be more likely to perceive a support group as potentially beneficial.

A variety of strategies for group therapy have been reported to reduce emotional distress and psychosocial problems of cancer patients. Supportive group therapy used in a recent study by Cohen and Herbert (1996) illustrates its effectiveness and compares it with a no-treatment control group. Supportive group sessions were non-directive and encouraged the sharing of mutual feelings. Group coping skills discussion/education intended to facilitate coping in common patient situations were explored. Homework assignments were set, individual goals (from a psychosocial perspective) adopted, self-monitoring was set in place with the use of a patient's personal diary, behavioural rehearsal and role playing was encouraged in the session to enhance confidence and generally re-build self-esteem while receiving feedback and coaching from fellow patients or the psychologist who was the facilitator. Results indicated a consistent superiority of the coping skills intervention on a number of measures including emotion, increased satisfaction with lifestyle activities, cognitive

distress, communication and ability to contend with medical procedures (Cohen & Herbert, 1996).

Helgeson and Cohen (1996, p. 139) used a group therapy programme called forgiveness therapy which focussed on the relief of negative feelings towards self and others where the patient realises that he or she cannot condemn anyone for the cancer. Some therapy sessions began with mini-lectures on specific topics (e.g., holistic approach to mind-body) and all sessions included the sharing of experiences by group members. The researchers concluded that forgiveness is a process with stages, that patients can draw inspiration and courage from the therapeutic value of the forgiving experience and the act of forgiveness can promote catharsis and peace.

This highlights the biopsychosocial interaction of an individual's feelings, thoughts and perceptions where changes in one area (e.g., a stronger, healthier perspective which helps the person cope better with the cancer) immediately impacts on other areas of that person's life. The psychosocial oncology literature as a whole also highlights lifestyle changes, communication with healthcare providers and relationship changes (including sexual functioning) as possible crucial variables in any group therapy.

More Recent Research into Interventions

Two recent intervention studies provide the most convincing evidence of a role of psychological factors in cancer progression. In one (Fawzy et al., 1995) sixty six cancer (melanoma) patients were randomly assigned to either a treatment or a non-treatment group. The support group intervention combined education, stress management, coping skills, discussion with fellow patients, and facilitator and consisted of 6 ninety-minute sessions. Six months after the intervention ended, participants in the intervention group showed reduced psychological distress, enhanced immune function and changes in immune cell counts (e.g., decreased T-cells, increased lymphocytes) when compared with patients in the non-treatment group. The intervention also decreased recurrence and increased survival as assessed two years later.

In the other intervention study, Spiegel et al. (in Cohen & Herbert, 1996, p. 135) randomly assigned 58 cancer patients to a treatment or a non-treatment group. The intervention consisted of weekly 90-minute meetings for one year and focused on various problems associated with terminal illness and on ways to improve relationships. Two years later there was an eighteen month survival advantage associated with the intervention. No immune measures were assessed.

These studies are conceptually important because they demonstrate the significance of psychological factors, and are practically important because they suggest a significant role for psychological interventions in cancer survival. Ongoing attempts to extend this work are encouraged by the authors to help evaluate validity and identify behavioural and immune mechanisms responsible for the reported outcomes (Cohen & Herbert, 1996, p. 136). This is valuable in the South African context where cancer patient support groups have not been reported. Cultural differences in attitudes towards illness (Sosha, in Pervan et al., 1995, pp. 316-317) suggest that these groups may be more socially acceptable in attempting to resolve psychosocial distress in cancer patients than the westernised guided imagery, hypnosis and relaxation methods.

Helgeson and Cohen (1996, p. 141) examine the associations of emotional, informational and instrumental social support to psychological adjustment to cancer. Studies suggest that emotional support is most desired by patients and that this form of support has the strongest associations with better adjustment. Health care professionals, it is pointed out, are faced with a new challenge: helping people live with cancer or live with having had cancer. An important determinant of cancer patients' ability to live with their illness is their social environment. There are at least two reasons why the social environment is a particularly important domain in the study of cancer. First, aspects of the social environment promote well-being and can protect persons from the harmful effects of stressful life events, such as cancer. Here, both the structural aspects of social networks such as size, and the functional facets of social supports (e.g., emotional support) have been related (by way of care management) to cancer morbidity and mortality (Helgeson & Cohen, 1996, p.145). Second, cancer is a stressful event that influences interpersonal relationships; the characteristic stigma

of the potentially fatal disease often results in the patient's network members withdrawing or reacting inappropriately. Cancer often affects relationships indirectly by restricting patients' social activities (particularly while undergoing treatment) which in turn affects their access to interpersonal resources. Therefore, people diagnosed with cancer may, from the first diagnosis, have difficulties obtaining social resources just when they are most needed (Helgeson & Cohen, 1996, pp. 143-146), which is where the support group becomes crucial.

Although the experience of cancer depends on individual characteristics, site of malignancy, stage of disease and type of treatment, people diagnosed with cancer confront many common psychosocial issues and, as a result, have similar needs that can be met by people in their social environment who can empathise with these common problems such as potentially arise in a support group of patients.

Emotional support involves the verbal and non-verbal communication of caring and concern. It includes listening, being there, empathising, reassuring and comforting. Emotional support can help to restore self-esteem or reduce feelings of personal inadequacy by communicating to the patient that he or she is valued and loved. It can also permit the expression of feelings that may reduce stress, and can lead to greater attention to and improvement of interpersonal relationships, thereby providing some purpose or meaning for the disease experience (Helgeson & Cohen, 1996, p. 146).

Informational support, in interaction with the emotional support, involves patients being provided with information so as to guide or advise. In a support group intervention, this information may be from fellow patients, facilitator, guest speaker or library material, which may enhance perceptions of control by providing patients with ways of managing their illness and coping with symptoms. This has led to a reduced feeling of future vulnerability and the sense of confusion that arises from the initial diagnosis of cancer to help the patient understand the cause, course and treatment of the illness (Helgeson & Cohen, 1996, p.146).

Instrumental support has both advantages and disadvantages. This support involves

the provision of material goods such as transport, money or help in the household and may offset the loss of control that patients feel during cancer treatment by providing tangible resources that they can use to exert control over their experience. However, this may also increase feelings of dependence and undermine self-sufficiency in patients.

Methodological Problems: How They Will be Met

Factors such as diet quality, sleep loss and drug, alcohol or tobacco use can affect immune function. A third-level factor, such as life style disruption, may be responsible for the cancer patient's immune system being further compromised and negate any positive effect of psychosocial intervention. These confounding factors will present a challenge to the effectiveness of an intervention. However, within the "safe" environment that the support group potentially provides, individuals may learn to cope with their unique problems (that is, they tend to be highly individualised) and come to manage not only their cancer but also their reaction to treatment and altered lifestyles (McCabe, 1991). In this regard Ader et al. (1991, p. 849) indicate more complex methodologic-al problems that arise in the context of cancer research. Potentially confounding variables include:

1. Medications, prescribed or "alternative", which may not only affect immunity but also have neuropsychological side effects. Although the medications may be valuable and positive, they may have an adverse effect and leave the patient extremely vulnerable in a support group situation.
2. Factors such as described above: Nutrition, drugs and alcohol.
3. Psychosocial interventions, such as a support group, should also be sensitive to various "new situations" relevant in a multi-faceted society such as South Africa. Gays and lesbians, drug-users and people from different ethnic groups and home languages who have cancer, must be seen by all participants as just as much part of the intervention as anyone else with cancer. They too need to be encouraged to participate

in and benefit from the group's activities where envisaged barriers and boundaries are gradually broken down.

Many of the factors may be raised and discussed openly in the group, once the patient feels the atmosphere is caring, sensitive and confidential. The language problem may be overcome through the use of an interpreter, possibly found among the medical staff. Other procedural problems while the intervention is in progress (e.g., a panic attack) can be countered by the psychologist as facilitator or the medical staff in the building.

Stress will be measured using appropriate questionnaires (these will be administered to the patients before, during and after the psychosocial intervention) and through continuous feedback from patient, group, medical staff and families. Problems could be managed in the group.

Small sample sizes of convenience are frequently cited as reasons why this form of research is low in generalisability when used without any control group. The counter argument focuses on the patient receiving more individual attention which creates greater opportunity for personal growth. Moreover, the transferability of common themes discussed in the group meetings, may assist future support group interventions.

Miller (1996) contends that long-term interventions are regarded as most beneficial to the cancer patient.

Helpful and Unhelpful Support

Helgeson and Cohen (1996, p.136) emphasise the most frequently reported (by cancer patients) unhelpful behaviour can be regarded as the failure to provide emotional support. Avoiding the patient, minimising the patient's problem and forced cheerfulness all keep the patient from discussing the illness. The availability of someone with whom the patient can discuss illness-related concerns is central to the concept of social support of an emotional nature.

Perhaps, it is contended, the reason that patients perceive the opportunity to discuss feelings, especially negative ones, as an important type of support is that this specific kind of support is rarely available. Patients often want to discuss worries and concerns including the symptoms of the cancer treatment but family and social network members believe talking about the illness is bad for the patients (e.g., leads to sobbing) and upsetting to themselves. In a study by Taylor et al. (in Helgeson & Cohen, 1996, pp.139-141) of support group attenders the majority said they wished they could talk more openly with family members. Dunkel-Schetter (in Helgeson & Cohen, 1996, p. 140) found that most cancer patients said they coped with their illness by keeping thoughts and feelings to themselves as they were concerned about how others would react to their expression of feelings.

Although a lack of emotional support from family and friends appears to be especially harmful, there are limits on the extent to which family and friends can provide certain kinds of emotional support. For example, reassurance ("Everything will work out") or empathy ("I know how you feel") when conveyed by family and friends. However, these same responses may be seen as genuine and helpful when conveyed by fellow patients (here, peers). Research suggests that peers are in a unique position to provide support because they do not share others' misconceptions about coping with cancer and they are not vulnerable to the anxiety and threat that discussing the illness poses for other family and friend network members (Helgeson & Cohen, 1996, pp. 140-141).

The helpfulness of support groups depends to a large degree on a certain structured format and the presence of a psychologist or social worker as facilitator. The facilitator keeps group members on track and reduces chaotic conversations, promotes acceptance and feelings of commonality as opposed to uniqueness and deviance, normalises and validates experiences, and clarifies misconceptions. After the rules have been drawn up in conjunction with group members, the structure within the group tends to manage and control itself.

Helgeson and Cohen (1996) examined the mechanisms by which one would expect social interactions to influence psychological and physical adjustment to cancer and

suggest that enhancement of self-esteem interacting with restoration of perceived control, instilling of optimism about the future, provision of meaning for the experience and the fostering of the patient's emotional processes are useful goals for any support group intervention. The intervention should last at least six months if the support group is to be an effective vehicle for providing the emotional support cancer patients require most frequently. The groups should meet in the same room, at the same time at least every fortnight on the same day. Previous research indicates that the group should not be larger than twelve and that the patients be at roughly the same stage of treatment or period of time since diagnosis. Kiecolt-Glaser and Glaser (1995) also report that the support group should contain only Stage I and Stage II malignancy and should only meet for 90 minutes to 2 hours at a time; this is because the stage of disease in cancer has a profound effect on how patients feel and the treatments such as chemo-therapy and radiation tend to tire the patient easily.

Fawzy et al. (1995) consider a structured intervention consisting of stress management training, coping including problem-solving techniques and psychosocial group support offers the greatest potential benefit for patients who are newly diagnosed or in the early stages of their treatment. Patients are usually distressed, anxious and unable to effectively utilise their normal coping styles. A structured intervention offered early in the course of cancer diagnosis and treatment may be less stigmatising and more readily accepted by both patients and staff and easily integrated into the comprehensive medical care of patients with cancer.

The advantages of such a support programme include easy implementation and replication, promotion of important illness-related problem-solving skills, and increased participation in decision making and active coping. The focus would be on learning how to live with cancer, daily coping, pain management (e.g., learning to take one's medication for nausea all the time - not just when the pain is extreme) and dealing with the existential issues related to death and dying (Fawzy et al., 1995).

Ader et al. (1991, p. 860) highlight a crucial variable in the life of a cancer patient and the focus of any intervention: social relationships. These social relationships in a

person's life (including that with God and with the self) do not simply have a correlational relationship to health but actually have a causal impact: studies that have controlled for a standard health status have reliably shown greater mortality among individuals with fewer relationships.

In an investigation of social relationships and the immune system interaction, Kiecolt-Glaser and Glaser (in Ader et al., 1991, pp. 849-867) highlighted an association between loneliness and immune function. Whereas loneliness can be a consequence of social isolation, the presence of others does not necessarily reflect support. Certain kinds of relationships may have harmful consequences; unsatisfactory relationships may themselves be a source of constant distress (thereby compromising one's immune function) while simultaneously placing limits on one's ability to seek support in other relationships. Therefore it is not surprising that poorer marriages are reliably associated with increased stress - unmarried people are happier on average than those in troubled marriages, and unhappily married individuals also report poorer health than either happily married or divorced people of the same race, sex and age (Ader et al., 1991, p. 860). This would be a very important topic in any support group intervention: the mere discussion of significant relationships in general and intimate relationships in particular would set the foundation for others to contribute their own idiosyncratic experiences before and after the diagnosis of cancer.

Conflicting Views: Difficulties Found with Support Group Interventions

Group discussion interventions potentially benefit patients' adjustment to cancer by enhancing their self-esteem through the provision of emotional support (Lieberman, in Helgeson & Cohen, 1996, p. 144). Discussion with fellow patients is focused on conveying caring and acceptance, reducing feelings of uniqueness and validating feelings through the sharing of experiences; that is, it is intended to encourage positive feelings towards the self or to diminish feelings of personal inadequacy that may accompany cancer. Mutual support and encouragement are intended to enhance patients' optimism about the present and the future. Additionally, the process of expressing the self in a sensitive and accepting environment may affect adjustment by:

(a) increasing the patient's awareness of previously unacknowledged emotions; (b) facilitating their access to new emotions; (c) encouraging their acceptance of emotions or (d) altering their emotions.

Helgeson and Cohen (1996, p. 143), however, point out that cancer group discussions have the potential to adversely affect a patient's reactions to the disease. They may also reduce self-esteem and diminish perceptions of control.

1. Support groups have the potential to negatively affect self-esteem and optimism about the future. Different personalities, different prognoses and different kinds of cancer can lead to harmful interactions where self-esteem is susceptible to damage through the reinforcement of the subject's identity as a member of a stigmatised group. Lieberman (in Helgeson & Cohen, 1996, p.144) suggests that these problems can be addressed with structured formats such as previously negotiated (patient with researcher) rules which state that each person's input to the group discussion is important and worth listening to in full.

2. Support groups may also reduce perceived control among some patients. One way cancer patients maintain control over their illness experience is by denying its existence. Group activity could break down denial which may increase distress, thereby further compromising the person's immune function. According to Spiegel et al. (in Helgeson & Cohen, 1996, p. 143) this increase in distress tends to benefit health in the long term if follow-up studies are undertaken and patients are monitored in a longitudinal project. Beneficial effects on adjustment, it has been reported, do not show up during the intervention but soon after its completion.

3. Emotional support from fellow patients in the support group may not influence well-being. It may be that emotional support from existing network members - friends and family - has a greater influence on adjustment than emotional support from other cancer patients. Rook and Dooley (in Helgeson & Cohen, 1996, p. 144) postulate that support groups need to be long-term so as to foster more natural friendships between patients.

Fawzy et al. (1995) maintain that whatever the support group for cancer patients

purports to be, certain things are clear nowadays:

1. It is not - and probably never will be - a "miracle drug" or panacea.
2. Although patients who have experienced this form of group therapy report marked benefits, it is equally true that others with newly diagnosed cancer overcome their difficulties through their own adaptive capacities and /or with the help of family, friends or members of the clergy who may provide counsel.
3. Individuals who have learned to cope more effectively with adult responsibility and who possess greater personality resources, derive more substantial benefits from this form of support than people who lack those strengths or suffer from emotional disorders of long standing.
4. No form of psychotherapy, including hypnosis, visual imagery and relaxation therapy, has emerged as uniquely effective except in some narrowly defined situations; which may include the psychosocial environment and the person's hereditary characteristics.
5. The extent to which prolonged group therapy produces radical reorganisation of a person's personality, and therefore lasting change, remains controversial.
6. The quality of the interpersonal relationships between fellow - patients and between facilitator/therapist and the support group patients plays an important part in determining the course and outcome of this form of therapy.
7. Finally, in view of the above mentioned considerations, the search for specific psycho-therapeutic techniques within the support group, given each person's personal qualities, may turn out to be futile.

Why, in the light of this apparently pessimistic picture, has this form of "cancer therapy" the potential to fulfil a need for cancer patients?

One possible reason may be that a great many cancer patients have a cancer prone personality. This Type C individual suppresses emotional expression, especially anger, and tends to be highly compliant and conforming (Holland & Rowland, 1989).

Cancer patients who join a support group are taught ways to vent their emotions

when some would otherwise have suppressed their feelings of anger. These techniques include role playing and behaviour rehearsal, as the group potentially provides emotional support through verbal and non-verbal communication.

Within the dialogue of the group the patient has an opportunity to reflect on his/her life at the present. The diagnosis of the disease usually indicates an overload of psychosocial stressors in the person's life. Drastic decisions need to be made in the "here and now" of the disease to eliminate as many areas as possible which the patient perceives as distressful. This would necessitate an honest appraisal of one's situation before the initial diagnosis of malignancy was made so as to examine areas where the person's immune system was gradually compromised.

Research by Trösborg, Knippenberg and Rijpma (1992) reviewed studies that compared treatment and non-treatment groups involving hypnosis, guided imagery and relaxation. They argue that only studies which have at least one comparison (non-treatment) group can be evaluated for effectiveness. Also, in a hospital milieu it is frequently impractical to randomly select and assign cancer patients to a group where they would be deprived of an opportunity to be part of a potentially health-enhancing support group.

In this study, the evaluation of the group effectiveness will be in the hands of the participants(including the researcher), given the constant feedback each patient receives from medical staff, peers, family and their own self-reported data from the questionnaires and weekly homework reports (Appendix G).

CHAPTER 4

PSYCHOSOCIAL STRESS AND CANCER: TOWARDS AN INTEGRATIVE MODEL OF MEASUREMENT

Miller (1996) contends not only that it is now common knowledge that stress can lead to physical illness, but also that accumulations of stressful experiences make physical illness more likely. At the same time, researchers are searching for more comprehensive ways of measuring the very individualised phenomena of stress so as to better understand the direct and indirect links to physical illness such as cancer.

It has been customary in stress theory, although not always in stress measurement, to distinguish between eustress and distress. Hans Selye (in Miller, 1996, p. 139) described eustress as pleasant or beneficial (i.e., curative) and distress as unpleasant or harmful. With regard to this distinction, research in the 1980s and 1990s measuring stress, classifies life events into positive and negative events, and distinguishes hassles from uplifts. Life events and hassles are the two types of psychosocial stress measures most often used in contemporary research; life events refer to major stressors that occur relatively infrequently and are typically measured over a one- or two-year time period. Hassles are minor stressors that may occur on a daily basis and are usually measured over a one- or two-week period. Since life events include more major occurrences such as marriage, divorce and death of a spouse, they can be recalled accurately over a greater retrospective period, but research has shown that this should not exceed six-months.

Weiner (in Miller, 1996, p. 104) highlights a category that has not been systematically used in stress research; namely, life time traumatic stress. Highly traumatic events, especially if experienced in childhood, could have long-term effects on health status. Items include child sexual molestation, life-threatening illness or injury, amputation, rape, witness of violent death and other such traumatic events. This project will assess change by the simultaneous use of the PERI Life Events Scale and the Daily Hassles and Uplifts Scale which include the following: Life time traumatic

stressors, threat - challenge appraisals summed over the traumatic stressors and stress feelings summed over traumatic stressors.

These integrative scales aim at a systematic measurement of existing distinctions in the theoretical literature. The integration will provide a better test of modern stress theory than would simpler models that ignore key distinctions, such as those among life time traumatic stress, life events and hassles; or between pleasant and unpleasant stressful events; or those among objective stressors, cognitively appraised stress and emotionally toned stress reactions.

Cooper and Watson (1991) analyse the diagnosis and treatment of cancer in terms of its stressful properties and restrict the wide range of definitions of stress to psychogenic stressors associated with cancer and its treatment. An event or an anticipated event is defined as a psychogenic stressor if it provides information that is appraised as having unfavourable implications or potentially unfavourable outcomes. Lazarus and Folkman (in Cooper & Watson, 1991, p. 183) have described the three types of appraisals that characterise stressful encounters: harm/loss, threat and challenge. Harm/loss refers to an appraisal of the extent of damage that is perceived to have already occurred. Threat refers to an appraisal that harm or loss can be anticipated. Challenge refers to an appraisal that there is a potential for gain or mastery in a situation that also has the potential for harm.

This definition of psychogenic stressors emphasises the role that cognitive processes play in determining whether or not an event is stressful. It is not the event itself that is necessarily stressful, rather the individual's interpretation of the event. So, the same event may have very different meaning for two individuals based on their individual appraisals of the situation. This definition stands in contrast with "objective" views which hold that certain life events (such as being diagnosed with cancer) are inherently stressful for all individuals.

The other aspect of this definitional approach involves the multi-dimensional nature of the stress response. There are three major components, and emphasis is on the

interactional nature of these components. Firstly, the emotional response: the experience of psychogenic stressors - that is, the appraisal that a situation is harmful or threatening - is usually associated with the subjective experience of negative emotional states such as anxiety. Secondly, the physiological response: physiological changes may be concomitants of the emotional response and of efforts to respond to harm, threat and challenge. Thirdly, the coping efforts; stressful circumstances do not take their toll on a passive individual, but on a person who is colouring stressful circumstances with personal meaning and struggling to control and master these circumstances. Any discussion of stress must consider the individual's ongoing cognitive and behavioural efforts to cope with internal and external demands.

The interactional nature of the definition (congruent with the interactional approach to the study) is best illustrated with three examples. The first involves the bi-directional relationship between appraisal and information. Appraisal is seen as an ongoing process which can influence the subsequent search for information. Based on the appraisal, a person may or may not seek additional information or may seek only information which confirms the initial appraisal (i.e., that a threat exists or that there is no threat). The second example involves the reciprocal relationship between emotional responses and coping. A powerful emotional response to a threatening situation may lead to a reliance on emotion-focused coping efforts (e.g., avoidance of thoughts related to the threat) which, in turn, serve to blunt the emotional response. The third example is that the nature of the stress response can shape subsequent appraisals; this is especially true when the psychogenic stressor is chronic or occurs repeatedly. Based on previous experience, the degree of threat an individual associates with a particular situation may increase or decrease over time (Miller, 1996, pp. 152-157).

During the course of cancer and its treatment, individuals encounter situations and information that lead to appraisals of harm, threat or challenge. The definition suggests that the impact of cancer-related psychogenic stressors should also be examined in terms of the emotional responses, physiological responses and coping efforts to which they give rise. There are characteristics of the individual that are important to consider

since they may contribute to differences in appraisal and stress responses. For example, a person who has strong beliefs about personal control over events may be more likely to view an event such as cancer diagnosis as a challenge and undertake problem-solving efforts. Situational factors may also affect appraisal and coping. Situations characterised by a high degree of uncertainty (such as awaiting biopsy results) create conditions likely to give rise to appraisals of threat.

Current Measures in the Assessment of Stressful Life Events

Are threat-challenge appraisals the result of feelings of being pressured and overwhelmed? As stress feelings appear to be more closely linked to physical illness it would appear useful to include a more cognitive and a more emotive component to the subjective stress reaction.

In this regard, Miller (1996, p. 209) summarises the measures currently utilised in assessing life stress events. Consistent across these measures (which include the scales to be used in this study) are three basic objectives. Firstly, the identification of experiences involving traumatisation and stress and subsequent symptoms, secondly, a consideration of the presence of coexisting psychological features and, thirdly, specificity with respect to the diagnostic and statistical evaluation criteria of the American Psychiatric Association and the international classification of disorders (DSM III-R, Miller, 1996).

The following are descriptions of the scales that are used in this research project:

Hassles and Uplifts Scales (Kanner, Coyne, Schaefer & Lazarus, 1981) (see Appendix B and C)

The Hassles scale consists of 117 items addressing "hassles" in the areas of work, health, family, friends, environment, practical considerations and chance occurrences. Examples include declining physical abilities, not enough time for family, concerns

about owing money and pollution.

The Hassles Scale yields these summary scores. Firstly, *frequency*, a simple count of the number of items checked, which could range from 0 to 117; secondly, *cumulated severity*, the sum of the 3-point severity ratings which range from 0 to 351 (3 x 117) and, thirdly, *intensity*, which is the cumulated severity divided by the *frequency*, which ranges from 0 to 3. This latter score is an index of how strongly or intensely the average hassle is experienced, regardless of the number (frequency) of hassles checked. The correlations between frequency and cumulated severity are extremely high ($R \leq 0,95$).

The Uplifts Scale is constructed in a similar fashion to the Hassles Scale. The Uplifts Scale consists of a list of 135 items that were generated using the content areas of the Hassles Scale as guidelines. Examples include relaxing, spending time with the family, using skills well at work, praying and being with nature.

Results from a comparison between these two scales and major life events scales undertaken by Lazarus et al. (1981), suggest that the pattern supports the hypothesis that hassles are more strongly associated with adaptational outcomes than are life events. Physiological symptoms that can be accounted for by life events can also be accounted for by hassles. Therefore, major life events had little effect independent of daily hassles. Results further suggest that hassles contribute to symptoms independent of major life events. In predicting symptoms, a substantial relationship remained for hassles even after the effect, due to life events, had been removed. And, the remaining relationship between hassles and psychological symptoms was generally greater than between life events and these symptoms.

**Psychiatric Epidemiological Research Interview -
Life Events Scale (PERI-LES)(Dohrenwend & Dohrenwend,
in Miller, 1996, pp. 215-216).
(see Appendix D)**

The PERI-LES was developed to measure such life events as love and marriage,

having children, work, family, divorce and loss of job, and other more minor events. A number of these life events have been shown to correlate with the onset of medical illness (such as cancer). The list of 102 items was constructed from a series of previous studies on stressful life events. Dohrenwend et al. (1993) , conducted research which aimed to assess the applicability of the scale. It was reported that the PERI-LES had technical weaknesses. Firstly, there was no reliability data on the frequency of occurrence of individual life events. Secondly, the samples that judges used in assessing the ratings of life events were too small to assure that group differences (e.g., ethnic background, social class and gender) were reliable.

Comparison: Daily Hassles and Uplifts versus Life Events

There is a growing body of multiple, independent assessment techniques available for providing diagnostic information about patients with stress-related disorders and traumatisation. Such instruments yield information ranging from background factors to specific response measures. The advantage of these instruments include the increased validity and reliability of diagnosis especially when two similar scales are used in conjunction, and then repeated (re-administered) after one, three and six months of an intervention. Multiple sources can provide the necessary ingredients for a convergence of the data obtained.

In the treatment of cancer patients where mind and body struggle for survival, it would be appropriate in assessing the source(s) of psychosocial distress to use both the Life Events and Daily Hassles and Uplifts Scales. Their reliability and validity has been demonstrated (Kanner, Coyne, Schaefer & Lazarus, 1981, pp. 21-23), and any intervention strategy would benefit from the knowledge obtained from the person on a frequent basis (to assess the effectiveness of the intervention).

Summary

An examination of the literature reveals evidence linking psychosocially-mediated immunological alterations with cancer. The review suggests that immune regulation by

psychosocial stressors and/or interventions may importantly influence health status but how social support interventions affect immune system function in stressed samples remains a rarely researched topic. Existing studies provide only suggestive evidence.

More research is encouraged of immune measures based on the role of the immune system in the person's cancer which may help provide evidence for a direct link among psychological factors, immunity and cancer. Although cancer is a very individualised disease, there are a number of common psychosocial variables such as chronic stressors and immune changes that may impact similarly on the course of cancer for the patients and arise in an intervention such as a support group.

The research process anticipates methodological (procedural) problems. These may be dealt with on a proactive basis within the confidentiality of the support group (within the hospital environment), where open and sensitive discussions are to be encouraged with each person and his or her idiosyncrasies.

Psychological support groups have been promoted to reduce the cancer patient's at times, psychologically unhealthy reaction to diagnosis. The content and duration of these structured groups will be designed to help the patient manage emotional distress, interpersonal relationships and communication skills amongst others.

There are, however, conflicting views and findings that pertain to support group interventions. It has been further advocated that only quasi-experimental psychosocial interventions with comparison groups can be evaluated for effectiveness. From every argument and counter argument there are lessons to be learnt for the proposed study. Therefore, this study aims to be a pilot exploration of group therapy aimed at identifying themes, processes and issues for more systematic investigation that would ultimately allow for the testing of hypotheses regarding the psycho-immunological effectiveness of cancer patient support groups.

a function of the stressor-support interaction. Ideally, a person's state of health combats disease and provides the necessary strength to cope with the demands of daily life. Secondly, although the person's support network, at the biopsychosocial levels of functioning, can be overcome with chronic distress (e.g., at diagnosis) resulting in the state of health becoming compromised and vulnerable to infection, the case studies will show how support from fellow patients, on a regular basis, may alleviate much of this distress.

Participants between the ages of 17 and 65 years old, male and female were recruited on a voluntary basis from the cancer clinic at Muelmed Hospital in Pretoria.

The data from the support groups was gleaned over the six month period beginning in February 1998 but including the researcher's notes from the initial, individual interview with each patient in January 1998. Sources include the Hassles and Uplifts as well as the PERI-Life Events scales, the diary kept by the researcher of experiences within each session and the patients' report-back forms which were usually handed back each week as part of their homework (see Appendix G).

The findings will be organised under these headings:

1. A Vignette
2. Scale results
3. Current stressors and supports
 - a) The first three months of group participation
 - b) After three months participation.

The patients have given permission for their Christian names to be used as it is felt that this will not be in breach of the confidentiality within the support group meetings. Furthermore, the patients who have agreed to their cases being reported, will be presented with the final document (prior to printing for binding) before the thesis is handed in for examination.

Ten males and thirteen females participated in the sessions, and the number of sessions attended ranged from 1 to 22 (see Table 1). Of these twenty three individuals the five who attended more frequently were selected for the case studies.

These five case studies document the practical circumstances of the patients' lives and the types of stressors to which they are exposed.

	MALE	SESSIONS	FEMALE	SESSIONS
Age				
31-40	1	7	2	4
41-50	5	3	7	36
51-65	4	54	4	21
Race				
Coloured	0	0	2	28
Asian	0	0	0	0
White	9	63	8	36
Black	1	3	1	3
Language choice				
English	7		9	
Afrikaans	3		2	

Table 1: Description of sample

The participants in a support group, on any one day, numbered between two and six. Patients frequently joined the sessions for the duration of their medical treatment which fluctuated, in this case, from attending between one and six sessions particularly if they did not reside in Pretoria. However, there were three male and four female patients who attended the weekly sessions on a regular basis and their presence was

particularly useful when new patients joined the groups. All participants had been diagnosed more or less two months before volunteering to join the group, although one of the ladies had recently been diagnosed for the second time; the first diagnosis for the same cancer being two years previously. Many patients lived in and around Pretoria, were white and non-white and either understood and/or spoke Afrikaans or English, since those languages were the options for the questionnaires (see Appendices A, B, C and D).

As of November 1998 the group continues to meet at the clinic in the same room every week on a Tuesday (for men) and on a Thursday (for women) from 14h00. The sessions last 90 minutes.

The research lasted six months. In addition to the pre-test administration of the questionnaires, they were also administered after three months and after six months as a post-test. The subjects kept diaries of events and completed their weekly homework sheets (see Appendix G), to invoke a sense of commitment and responsibility to themselves and the group and so that the researcher/facilitator could keep abreast of positive and negative events between sessions within the group. The support groups continue and new patients join. To this end, follow-up studies may be arranged. All results will be shared with the patient and medical staff but confidentiality will be respected.

Recruitment of Subjects

At a meeting in early January 1998 the project was presented to the medical staff at Muelmed Hospital radiation clinic by the researcher. In this discussion constructive suggestions were made concerning how recently-diagnosed male and female cancer patients between the ages of 17 and 65 years old were to be introduced to the researcher for the purpose of forming and running the support groups. It was agreed that a short letter (Appendix E or F), introducing the researcher as both a cancer survivor and a research masters psychology student would be presented to the patients

by either the team of radiographers, the specialist-on-duty or the receptionist. This would briefly inform the patients about the intended study and invite their voluntary participation in a support group.

At the initial interview with the patients, the researcher elaborated the motivating factors behind the fellow-patient support-group intervention as an opportunity to discuss any distress of a psychosocial nature with which they felt burdened. A conference room had been allocated by the specialists for the purpose of conducting the support groups and it was there that patients were first interviewed and asked to complete the necessary questionnaires (see Appendices B, C, and D) and the accompanying consent form (Appendix A). The patients were also informed of the additional distress which may be evoked by participating since the support group potentially allows for and stimulates the discussion of previously unresolved psychosocial distress albeit in a caring atmosphere. The additional distress also pertains to the pre-test questionnaires but, since they were administered in a sensitive manner, this could be considered a minimal risk situation.

Each patient was then asked which afternoon during the week he/she preferred to attend the group meetings; either a Tuesday or Thursday was suggested as being more convenient to the medical staff. It was then explained that having chosen a particular afternoon it would be best to remain with that particular group since each group tends to progress at a different pace and reach a sense of trust and friendship at different times. The confidentiality of the meetings was emphasised as crucial to the willingness of the patients to discuss important distressing issues in their lives.

The medical staff agreed that the recruitment of cancer patients for the support group would be an on-going process and interaction among researcher and staff included monthly meetings at the clinic for reciprocal feedback and daily communication for the exchange of new ideas and other information.

The Support Group in Action: Step by Step

Introduction

Initially, when, from the first week in February 1998 participants had formed themselves into "men on Tuesday" and "women on Thursday", the researcher introduced topics for discussion (e.g., forgiveness, the pain of the loneliness of cancer and knowledge about the particular patients' cancers). Both the male and female groups began with three patients attending. Cooper and Watson (1991) refer to stages of such a support group, but these were not to be a natural progression. Cancer patients who have been recently diagnosed often need emotional and other kinds of support immediately and need to talk about many issues (e.g., fears and anxieties about the possible disruption of daily routines) in a short space of time.

In some sessions, many topics were covered, and in others, only one or two unforeseen topics such as drawing up a will or how best to cope with one's new enforced diet. The groups evolved at their own slow, but determined pace as was evident from homework feedback and when a new patient joined the group. Then, previous topics were aired with a degree of spontaneity from the regular members.

As the group grew in numbers from the 3rd February 1998, the patients introduced themselves and gave the group a little of their background; anything with which they felt comfortable. A new patient would go through the same procedure and meet the others as they in turn told him or her about themselves in as much detail as they cared to divulge. Then the rules were discussed. Cooper and Watson (1991, p.179) advocate a structured environment at first, suggesting that rules be adhered to such as: Only one person talks at a time with no interruption; questions are allowed after the person has spoken. Punctuality is expected, but should one not be able to make a group meeting a telephone call to a group member or clinic staff member or researcher is required. Transport can be arranged among fellow patients but notification of problems should lead to other arrangements being made. These rules were adopted by the groups at

Main Body of Each Session

The group meets to share experiences, initially concerning their physical status as treatment begins, but gradually feelings are evoked which potentially bring unresolved psychosocial issues to the person's conscious level. Deeper feelings are shared as the patients begin to know each other better and trust each others' confidentiality and group support is given in any way possible:

1. Generally, each patient used the group to vent feelings which were the result of problems experienced elsewhere and, with encouragement and feedback from other members or the researcher, he or she began developing coping skills.
2. The group required and acquired a great deal of diverse information from other members' experiences, thereby enabling individuals to build up their own particular knowledge. The researcher was often called upon to provide medical information from his university's library.
3. The topic of forgiveness was found to be useful as it often relieved negative feelings towards oneself and towards others. The patient "doing" the forgiving slowly realised that he or she could not blame anyone for the cancer and the process eventually led to a sense of catharsis and peace.
4. The subject of the patient's sense of loneliness was frequently raised. A wide variety of changes take place (after the diagnosis) in all his or her relationships (ranging from the relationship one has with oneself to the one, one has with God), in one's lifestyle and in one's sexual functioning. Discussions also focused on each patient's social environment as they may or may not promote well being and a feeling of being protected thereby engendering crucial emotional support.
5. The patient's perceived stigma frequently led to discussion. The problems mounted up after diagnosis of obtaining and maintaining the social resources required to support his or her significant interpersonal relationships(one lady reported the relief she felt when she found a suitable wig during her chemotherapy). The bi-directional nature of

the stigmatisation process in interaction with a support network of interpersonal relationships, was one of the challenges the support groups faced. Fawzy et al. (1995) contend that emotional support, in the form of verbal and non-verbal communication of caring and concern, where listening, being there, empathising, reassuring and comforting, is capable of overcoming the patient's increasing stigmatisation and decreasing social support. This became more evident when, in May, one of the ladies in the Thursday group died, all the members of her support group attended the funeral together.

6. Behaviour rehearsal and or role playing was encouraged to increase confidence and re-build self-esteem (e.g., learning to say "no" when it was necessary, say, after chemotherapy and a family friend invited one out). This required feedback (constructive) and coaching from fellow patients and others present. This facet of the support group activity led to better coping skills with emotional issues, more satisfaction with gradually changing lifestyles and more open communication with significant people in each patient's life.

Conclusion of Each Session

After ninety minutes or so, the researcher summarised the contents of the meeting and homework sheets (see Appendix G) were distributed. These focused on the person's individual experience of that meeting and anything else (e.g., any physical pains) the patient felt he or she would like to share with the group and/or mention in the diary. The following date was confirmed a week ahead. Transport issues were discussed and resolved before the following meeting. Group members often contacted each other between meetings, bearing in mind that confidentiality rules were not broken.

CHAPTER 6

THE RESULTS: THE CASE STUDIES

Introduction

The descriptions and observations of five cancer patients participating in the weekly support group over six months will be presented. The dynamic interaction of the small groups meant that each session affected each patient in unique ways as new topics were explored. In the moments of sharing experiences, empathy was found to be more empowering than sympathy and listening more compatible with altruism.

The situation is described in sufficient detail for the reader to sense that he or she knows these participating patients, and, gradually, too, the atmosphere in the support group milieu as well as being able to recognise the dilemmas present in the situation. Some of the facts have been altered to preserve confidentiality or provide emphasis, but in all essentials the cases follow events as they actually took place.

There are several objectives to the case study method (Houts & Leaman, 1983). One is to help readers to examine the situation (the complete cancer patient, in and out of the support group in his or her various milieux) as a whole and relating information to the interaction of decision and action. An example would be where one patient in the group listens to another's problem and, while relating it to his own situation, decides he will take similar steps, and does. Another objective is to help readers perceive which elements in a situation are the significant ones. Ultimately, the multiple aspects of a situation become so ingrained into the reader that he or she may be regarded as a participant observer.

The material for the case studies presented here was derived from:

1. Notes from the initial interview when the patient first met the researcher.
2. Data gleaned from the Hassles and Uplifts Scales as well as the Peri-Life Events Scale which were administered to each cancer patient before joining the support group at the initial interview, again after three months and again after six months of participation.
3. The journal kept by the researcher of themes and issues of each group meeting.
4. The feedback from the weekly homework sheets(Appendix G).
5. Telephone conversations that the researcher occasionally had with the participants.

Case Study 1: Richard

Vignette 1

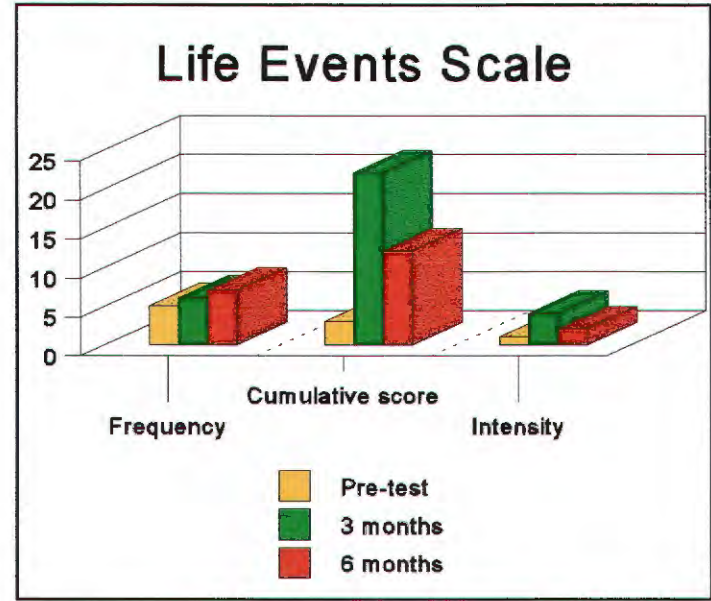
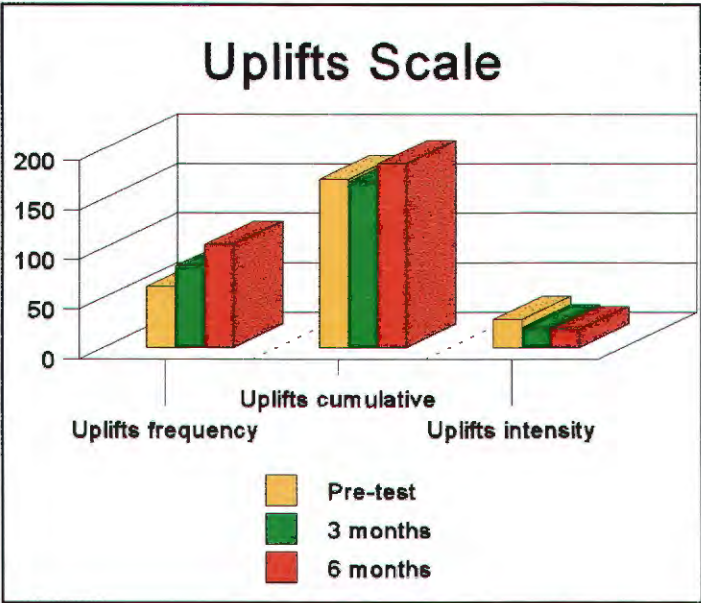
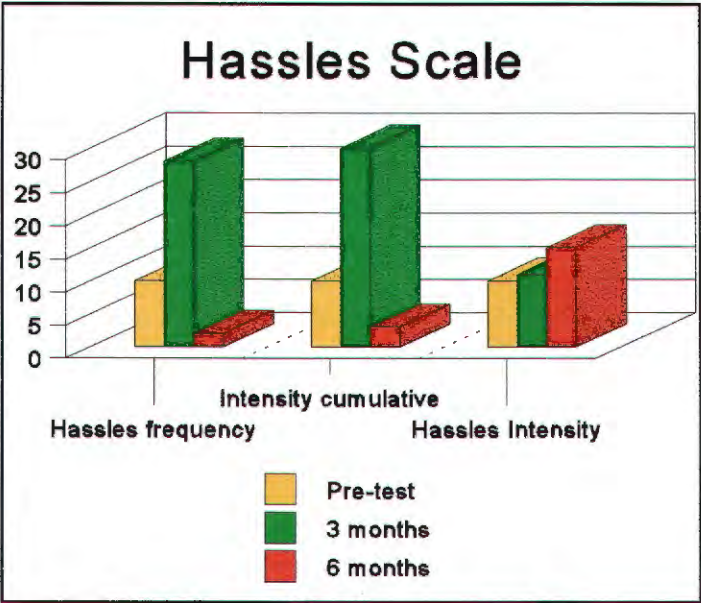
Richard was diagnosed with prostate cancer at the end of 1997. There are no known blood-relatives who have had cancer diagnosed. He is a 58 years old, English-speaking white South African who, with his wife, is employed in the estate agency business. They have two daughters and one son in their thirties. His financial position is not a cause of concern and his medical-aid manages his cancer treatments adequately. He reported at the initial interview that he was distressed about his large body mass, lack of regular exercise and dietary habits. He reported a previous life-style of running a farm and being extremely healthy. He concluded that since he had lost control over his body he would have a battle to regain his former state of health. This he maintained would be a daunting task by saying: "I have never been a fighter in my life".

Scale Results (see Diagram 1)

Richard completed the three scales at the first interview with the researcher in January 1998. The results of the Hassles scale showed that he experienced 10 incidents where he reported feeling a little distressed in each situation and this

DIAGRAM 1

Richard.
* multiplied by 10
for display
purposes.



corresponded with the Life events scores where he reported that in June 1997 he was the victim of a robbery which had led to an ongoing concern about crime (especially car-highjacking as he travels a great deal) and security for his family. However, these two scales scores revealed more concern about how his sense of losing control over his body had begun to effect other areas of his life. The Uplifts scale revealed 61 areas in his life in which he had found much fulfilment in the previous month.

After three months participation in the weekly group sessions, when he had returned from a 10 day holiday with his wife at the end of April, Richard's results from the re-administered scales showed nearly three times as many Hassles as he had recorded previously. However, their overall intensities (reflected in the "intensity cumulative" score) remained consistent so that the Hassles intensity (the cumulative scores divided by the frequency) was only fractionally higher than three months prior. These newly reported hassles arose within the workplace as he attempted to compensate for his loss of control in his bodily functions by exerting more control in "at least one familiar environment"(interview extract).

The Uplifts scale after three months showed twenty new areas which brought Richard pleasure. This was tempered by a reduced intensity of enjoyment overall. He told the researcher that he was feeling better despite the hormonal treatment. He had also begun to sing more often which tended to calm him after a long day.

The Life events, although only a few more were recorded than before, were experienced more positively. In the ensuing discussion he attributed this to his group participation, less panic about his cancer than three months previously, a new family dog, successes at work, a short holiday and his wife's loving support. This corresponded with the results of the Uplifts scale but did not agree with the increase in the amount of hassles. He felt that the hassles could have been there previously, but that after three months of meeting with fellow cancer patients who had similar problems he felt more confident about reporting them.

After six months of participation in the Tuesday group, Richard again completed the questionnaires. His only two hassles at that time were his excess body mass(hormone treatment related) and wanting to know more about the meaning of life. The Uplifts scale indicated another twenty two new pleasurable situations but, due to a slightly increased intensity in each item marked, the overall intensity dropped fractionally. The Life events scale highlighted the fact that Richard derived more positive emotions, the greater his workload. At work he constantly met new people and this factor helped him enjoy each day.

The trends in these results portray more hassles over three months of regular attendance being offset by his successful search for increasing areas of upliftment as supported by the outcome of the Life events scale. The scores after six months show reduced hassles while the frequencies of uplifts and recent life events again show similar trends as do their respective intensity scores.

Current Stressors and Supports

The First Three Months of Group Participation

Richard attended the first group session with one other patient, on Tuesday 3rd February 1998, with a great deal of enthusiasm and determination to fight his disease. He indicated that in his childhood he had never been a fighter and had always looked for a way out of any confrontation. He found it remarkable that since his diagnosis, all he had been doing, thinking, feeling and saying was that he must have a fighting attitude towards every aspect of his cancer.

He mentioned that an open and honest relationship with his wife, Sue, and his faith in God helped him in moments of "feeling a bit down" (Richard's words). He remarked that he experienced great pleasure from singing (anything) and being with other people especially children. At work he found delegating very stressful as he preferred to take on the responsibilities himself. His motif at the time was: "nobody can do it better than

me”(an extract from his homework) so why, he argued, must he worry about others making a mistake when he would have to undo it all later and still do it himself? He confessed to the group that this attitude left him overburdened and distressed when meeting deadlines, although he enjoyed the new-found sense of control over his life that meeting target dates gave him.

At that point, the other group member interjected that his hectic life-style probably had much to do with his cancer. He felt that, having lost control of his body with this cancer, he must look to other areas to exert control anew. His never-say-die attitude had an almost overpowering affect on the other group member to the point where he tried to dominate every person's contribution before that person had completed what he intended to say. Nevertheless, he made many, invaluable, empathic contributions which the other patient appeared to appreciate.

Richard soon discovered that his sense of humour was highly valued by other members. His love of fun and genuine laughter at various situations he had found himself in during his life, served to lift spirits despite the serious nature of the sessions.

At the onset of the support group meetings he was having radiation and hormonal therapy. The radiotherapy caused great distress. His bladder and bowel movements went “haywire” and affected his sleep patterns (to the point of insomnia), his work routine and his family life. Since another group member had experienced the same discomfort, it was suggested that plenty of fluids might solve his problem. This suggestion worked well for him and the relief felt by all his family and friends was considerable. The medical staff pointed out that this fluid intake should be at least one and a half litres of fluid (preferably fruit juice) every two hours. They then gave Richard a list of dietary do's and do nots to control the diarrhoea. He reported to the group that this newly acquired knowledge was a real blessing; it had helped to restore a little more of his confidence, add a little more control over his whole life and invoked more hope for the future.

From the homework feedback, this newly-acquired knowledge had an encouraging effect on the whole group and all members asked the facilitator/researcher for photostat copies of notes on their particular diseases from the reference manual that was always available at the group sessions. At this stage, the support groups had sorted themselves out into "men on Tuesday, women on Thursday".

This arrangement was not planned by the researcher but turned out to be satisfactory for both groups' members. Both felt that mixed sessions would inhibit conversations about sensitive issues. This became evident when Richard eventually began to speak about his impotence. He mentioned too his anxiety and being "a little down" when he began hormonal therapy. The group's reaction was to admire his openness and honesty. One patient remarked that he also had something similar to share with the group, and so honesty became the corner-stone of the discussion.

In this vein, Richard confided in the group that, 14 years previously, his eldest son had been killed in a farming accident and that he had been there when it happened. He added that in order to cope with the tragedy he had told his wife to "block out" (Richard's expression) all the unpleasant memories, and had done so himself. This, he claimed, was the first time he had brought it out into the open since it had happened. The affect of this revelation on the group was one of silence. He had everybody's attention and then elaborated further about how it had actually happened. The atmosphere in the room was emotional as he recounted how he had held his son when he had died. The group offered sincere encouragement in what lay ahead for him and his wife. It was then that everyone swapped telephone numbers so as to be available for extra-support, should it be needed.

Richard, in his homework feedback, still maintained that there was a place for a short-term "block" just to help one over the initial shock. While, most of the group agreed, some felt that it was not being realistic to deny it had happened, and that "surely, being honest with oneself would lead to less distress in the long-run?" The effect on the immune-system of long-term(chronic) distress was well known to some of

the group who had asked for extra information, so the topic led to a discussion where Richard admitted that, "now with cancer", it was a good idea to make another drastic decision and not to "block" any worries, anxieties and emotions. He would try to be more open in dealing with them. It was from this topic over a series of sessions about the unhealthy habit of denying one's emotions and how cancer recovery tends to force one to make adjustments, that the group decided on a motto:

The 5 D's: Dread Disease Demand Drastic Decisions

Richard's body mass increased substantially during this period but he appeared reassured when the facilitator shared his own experiences of chemotherapy with the added cortisone which only has the "ballooning" affect during treatment and quickly dissipates within a few months after treatment has ended. This returning to normal after many months post-treatment also applied in the case of impotence.

Richard shared with the group that he struggled to relax but when he does make the time, he enjoyed listening to music. This prompted group members to ask him to bring some of his favourites to the next meeting. He remembered this but forgot to bring his homework, which the others had done and brought along, much to his (apparent) embarrassment which led to "promises" (one of Richard's favourite words) for the future. He then initiated a lively discussion by saying that he had a problem with commitment and always had experienced this. The other group members reflected where they stood with this topic and Richard led the conversation towards making a commitment to God as a Christian. The topic of Christ the Saviour then led to much sharing of experiences among group members. All present agreed that it was appropriate to their current disease that they renew their faith in the Lord and allow their lives to be enriched by His daily presence.

Richard then suggested to the group that homoeopathic and naturopathic supplements to medical treatment for cancer, with a focus on enhancing one's immune system, were beneficial to him. The response from the other group members was to

ask for more knowledge about the immune system and its relationship to their cancer. This led to distribution of recent literature (in the form of photostat copies of journal articles about psycho-immunology, oncology and even endocrinology from the UNISA library) on the patients' need to know as much as possible about their condition. Each person present seemed to have had some experience with the term: "immune system". Richard actually brought the latest, advertised homoeopathic supplement (potato root extract) which led to heated discussion about its effectiveness and cost. The group then requested the facilitator to ask Dr Georges de Muelenaere (on duty at the time) to come to a meeting and explain all the questions that remained unanswered about these supplements. This was done. The doctor replied that he was willing to attend any group meeting after 15:00 at the clinic, provided all the questions were ready and listed so as not to waste any valuable time. The human immune system became the subject of much discussion in future sessions and revolved around topics concerning psycho-social distress and how this compromised one's immune functioning.

Richard, in this regard, asked about "cure" and especially "mind-body cure" for cancer. His homework referred to information he had concerning "holistic" treatment and he needed to know more details about this approach. The researcher elucidated this in detail as it corresponded with the approach of the present study. Richard understood the term "biopsychosocial" as best elucidating the interactional approach to cancer treatment. This pertained to the prospect of all health-care professionals' attitudes towards the cancer patient's treatment being in line with this approach, which would give the person an optimal opportunity for a lasting remission. Some doctors, he reported, claimed that a remission with annual check-ups of the person's blood counts showing gradual improvement after five years since suspension of treatment, would be regarded as a cure. Other specialists seemed to be more careful about using the word "cure" and preferred "remission". They argued that after medical treatment had been completed, it was up to the particular patient's own internal and external variables (see earlier diagram of the Interactional Model) whether the remission endured.

Towards the end of the first three month period, Richard asked about being in touch

with one's "real" worries. The consensus in the group was that the Creator had provided two natural ways of coping with any worries: talking about them to at least one, trusted confidant which may lead to the second natural way where the person's emotions evoke cathartic tears.

Both tended to have a cleansing affect and frequently left the person feeling restored to a sense of well-being. Richard agreed and mentioned that it had recently worked for him, since his diagnosis of "old-man's disease" (Richard's expression). He mentioned that he had a very strong relationship with his wife and that it was she who provided the occasional shoulder for emotional support.

At the end of April, he took his wife away on holiday for 10 days. Before he left, he admitted to the group that he could not relax. This led to much supportive advice from the group which he tried to implement. He reported little success. His report back to the group was rich in all the anguish he had experienced of the delegated work to be done in his absence, not being done to his satisfaction which left him to clean up the mess. However, his Faith helped him enjoy some of the time and he said he felt relieved to be back in the support group which, he said, gave an added sense of control over his cancer.

After Three Months Participation

On the 13th May, Richard heard from his oncologist that his cancer, with a mass at diagnosis the size of a fist, had reduced to the size of his small-finger nail. He had been extremely anxious the day before, at the Tuesday meeting, as he was awaiting the results of scans and blood tests. The researcher heard this great news from the oncologist concerned, as both had attended a quarterly research- feedback meeting at the cancer clinic in the afternoon. The medical staff were pleased as were all the group members. Richard had recently become very health conscious and coupled with the latest medical news, served to cement all the forced changes he had made in his life up to then.

In his quest for more and more knowledge about cancer and about his in particular (prostate cancer is the second most common cancer in Western countries, the cause of which is unknown but is possibly due to the influence of steroid hormones and living in an urban environment [Pervan, et al., 1995, p. 462], Richard reported back to the group on all his latest discoveries.

Richard shared his new successes at work with those present (three others, on this occasion). He felt relaxed with his medical results and laughed more frequently which was a source of inspiration for the whole group. He spoke openly about his new hope and how he did not feel so lonely anymore. He emphasised the loneliness of cancer.

In retrospect, he found that by talking and talking in the group, it gave him more confidence to talk to people outside of the group about his cancer. His present condition he referred to as: "not gone but under control". By the end of May, all had taken heart at his cancer's turnabout. He was also full of praise for his Lord Jesus and his strengthened Faith infused the group with more hope.

At the end of May, Richard had a positive affect on a new group member. The themes of the discussion at his first meeting, ranged from the immune system and how cancer could turn out to be a blessing if the newly diagnosed patient made serious and lasting changes to his lifestyle, to coping with relationships. Although overpowering at times, Richard's enthusiasm for showing group members the road to recovery and then explaining the aspect of "training" oneself to adapt to the new lifestyle that cancer demands, left the new member in no doubt that his cancer could be beaten.

Richard also told the group that his lifestyle contained less hassles and more joy since the most recent medical results. The group immediately responded by saying that, that was no time to be sitting on one's laurels and agreed that, instead, he should be continually aware of his predicament. He used the "magic word NO" (he reported that he previously had a problem using the word, so when he had acquired the confidence to do so, it had felt magical) when he honestly felt that his body was indicating that it

needed to rest. Even when he was being tempted to ignore the signals and wear himself out in some activity (as he had done so in the past), he put his health first. He began to firmly entrench the recent decisions he had made about changes in his lifestyle that put him on the road to recovery in the first place. This, so that when he did go into remission the actual changes would already be normal routine. Other members present agreed to follow his example.

Richard still had a long road to travel: his hormonal treatment still resulted in a great deal of discomfort and concern but he felt more confident when speaking openly to his doctor about the side-effects. He reported that there were now no areas where he felt afraid, restrained or embarrassed to discuss with the medical staff.

At the end of June, he experienced problems with his balance as his ears seemed to be blocked and very painful. He quickly had this attended to by having his ears syringed on more than one occasion. At this time some new-comers to the group experienced a great deal of fear and uncertainty about their own futures. In this regard, Richard reassured many patients with reminiscences of when he had doubts about his future and how, by having a "rock-solid faith", he trusted God sufficiently to thank Him for each day as it dawned while knowing that he did not yet need to know what tomorrow held until it arrived. This attitude held out a little hope for the new arrivals and helped the conversations to focus on the "here and now" of cancer. Richard frequently used the phrase "What If" mode, in this regard, when referring to the futility of worrying about the future when the cancer patient needed to focus on "today, every day". The discussions around this topic served to lift some down-hearted spirits.

This is one case of a South African, white, male, aged 58, with recently diagnosed prostate cancer. He decided to join a support group of fellow-patients in order to discuss psychosocial concerns with others in a similar predicament, while receiving medical treatment for his own condition. Over the six month period of this study he attended nineteen support sessions.

Case Study 2: Linda

Vignette 2

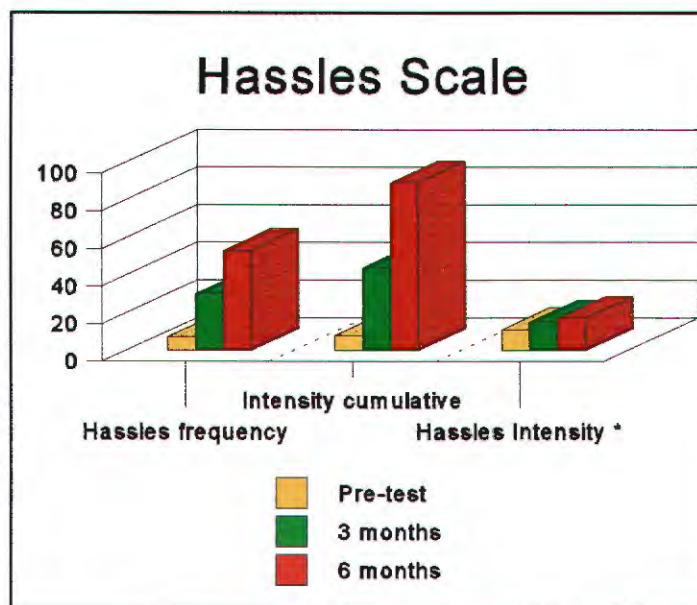
Linda is a 45 year old, South African, coloured woman. She lives in Eersterus near Pretoria and reports a long family history of cancer. Linda was first diagnosed with breast cancer in January 1996. The disease is common in peri-menopausal women between thirty five and fifty five and there is a definite family history. It also appears to be diet-related (Pervan et al., 1995, p. 404). Her first mastectomy was in the same year and the second followed one year later. She then had chemotherapy for a lump under her arm as the cancer had spread to her lymph system. The subsequent radiation therapy finally removed the lump in January 1998 and her disease went into remission in March of the same year. She is still required to have check-ups every three months so the attending oncologist can monitor her immune system through the blood samples that are drawn on each occasion. She reports living in constant fear that she may have to endure "the pain of chemo" ever again. She states that if the doctor says she has to, she will refuse. Moreover, she has managed over the last two years to reduce her smoking habit from a packet a day to only a few, now, that she feels she cannot do without: "I live for the pleasure a few cigarettes give me each day".

She is employed by a major bank in their trust division, which also provides transport in the form of a company bus; she is picked up and dropped at home every day. She is a single mother and raised her son and daughter who are now young adults, alone. She struggles financially and her neighbourhood offers little encouragement to change. She reports feeling trapped in her environment and being a victim of apartheid which held out little if any hope for the future or aspirations for advancement with hard work.

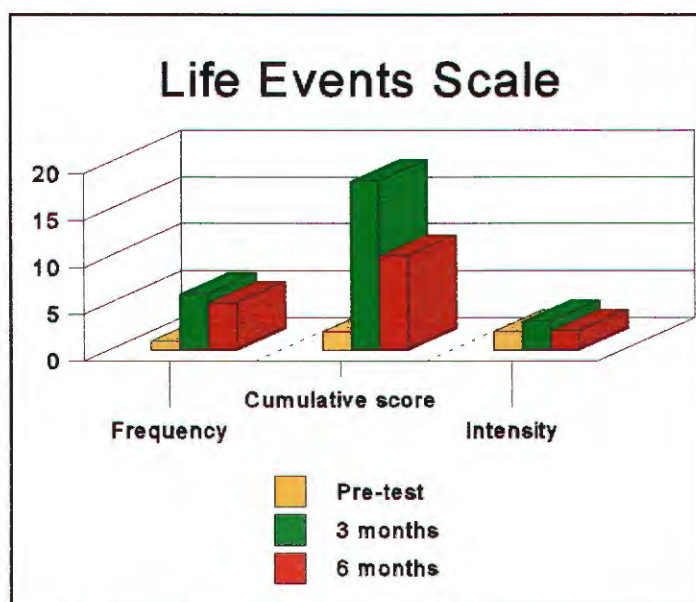
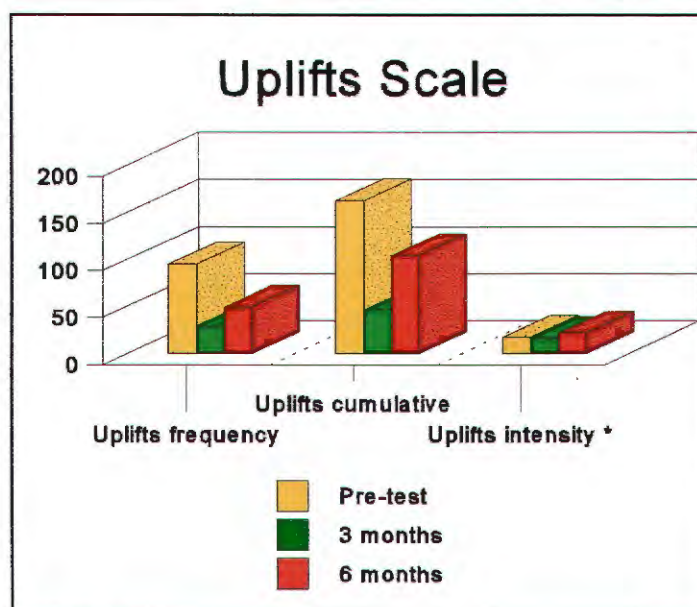
Scale Results (see Diagram 2)

Before she joined the Thursday support group, she reported in the first interview with the researcher and in the pre-test questionnaires that she was not experiencing any

DIAGRAM 2



Linda
 * multiplied by 10
 for display
 purposes.



Life events stressfully and appeared to be coping with her disease. Her only major cause for concern which presented only in the Hassles scale was the health of her daughter, Natasha. Other concerns mentioned in the scale were an on-going fear about her own future and the multi-faceted pain she experienced with cancer.

It was noticeable from the data in the pre-test Uplifts scale that Linda experienced much happiness in a various situations. She recorded 95 sources of upliftment and the scores indicated that her boyfriend, Andries, her children, her friends at the bank, and smoking her cigarettes were areas of most enjoyment. She mentioned to the researcher that these areas were good buffers against thinking about her condition too often. In the graph, the accumulated scores on the scale were high which served to give a low overall intensity. The pre-test scores were in line with her exuberant and friendly nature coping with the reality of her biopsychosocial situation but do not convey her despair over her recent relapse of her cancer. She was trying to manage by not letting the diagnosis effect her lifestyle.

At the end of April, Linda completed the three scales. The Life events showed positive improvement but on examination, the very positive(+3) items recorded, were the same as the Uplifts three months prior. What stood out after three months, was the indication of four times as many areas causing her hassles and one third as many areas leading to upliftment for her. The latter reduction also showed that those areas which previously led to much happiness for Linda, then showed much less satisfaction. The researcher questioned her about remaining in the group as it may have led to the reversal in her quality of life. She chose to continue attending and mentioned that she was only concerned about her cancer and the chemotherapy pain.

After six months of group participation, Linda again completed the three scales. She reported nearly double the amount of hassles than three months previously even though she claimed in a group session that her problems at home were less stressful despite being irritated over having all the financial responsibilities added to her daily housekeeping chores. This contradiction served to highlight the limitations of self-

report questionnaires in accurate measurements of points of distress in a seriously ill person's life. In discussion with the researcher she mentioned her distress about her daughter pervading all her thinking and effecting her decision -making skills.

When referring to her Uplifts scale responses which showed an upward trend in frequency than had been the case in late April in conjunction with more positive individual scores, she attributed this to her boyfriend Andries being more caring and affectionate, her close friends at work being more attentive and her reduction of her daily smoking. Her life events responses were fractionally reduced in number but her scores on individual items were more positive which gave a lower intensity than three months previously. These results are in line with the indication that Uplifts rose after falling to the three month low. However, this was not in line with the upward trend in frequency and severity of Hassles. The further contradiction came from the group where the impression she gave was mostly positive and happy in her interactions with other members and the facilitator. It appeared that the Life events outcome combined with the strengthening uplifts served to balance the intensity of the hassles, allowing Linda to achieve some small sense of control in her life while remaining cheerful in the group meetings.

Current Stressors and Supports

The First Three Months of Group Participation

From the first Thursday in February, Linda sat silently with her arms crossed and listened to everyone else in the support group. When she was eventually drawn into the conversation by one of the others asking " what cancer do you have?", the response was just "breast". This led to another woman comparing her breast cancer, its treatment and ultimate removal to Linda's, trying to get her to expand further. She would not. Eventually it became apparent that she had not yet come to terms with the fact that she had cancer-even after two years of treatment. She further admitted that she could not say the words: "cancer" or "disease". She then told the group that in talking to friends

and family she had circumvented the subject of "her health" for so long and so deftly that not even her children or mother knew what she was going through. The "siekte" was merely passed off as something for which she had to go for treatment occasionally. She told the group that she realised she was beginning to believe her own stories. She loathed too many questions when some neighbour began to pry. Her employers, who do know of the diagnosis, are very concerned about her health and at the same time supportive of her having the best available treatment. She has an adequate medical-aid scheme and her manager contacted the researcher at the cancer clinic to emphasise his total support for any help Linda may require. To this end, he asked that a letter be drawn up detailing the times of the support group so that transport could be arranged to and from work. He also requested the doctor's signature as this document would go on her file so that there would be no pay reductions for time away from work. This was complied with immediately and Linda felt a great sense of relief. She confided that she has many friends at work but only her closest know about her condition and are always helpful and friendly when she has to go for any treatment.

The group decided that it may be helpful to Linda if there was a little behaviour rehearsal where she would play the role of an open and honest cancer patient and the group would represent friends and family. Everyone present enjoyed Linda's response (the homework feedback also referred to the fun involved, e.g., "enjoyed Nick's acting" and "Nick you missed your vocation"). She reported feeling more confident and better equipped to cope with people asking questions (even her doctors) about her health. She realised that many were trying to show love, support and caring but were not being let through the "barriers". Her homework revealed that she had made an effort to disclose this information to close friends ("my bure" [my neighbours]); some people who she felt would not sit in judgement of her.

She began to smile more and told the group she felt relieved that it had been discussed and apologised for taking up so much of the group's time. The group, in turn, were greatly relieved that she had "broken the ice" on the subject of openness, honesty and the stigma of cancer. This led to other patients in the group giving their own input

on these topics with recent experiences. Linda seemed to draw strength from this as soon as she realised her problems were not unique.

The researcher provided Linda with recent research articles which explained in layman's terms the effect of pent-up distress on a person's immune system. The group members were keen to know more about this relationship and details were provided. Linda began to open up more often when she realised her problems had sparked a chain of related discussion topics.

At the end of February Linda read a beautiful letter from her 21 year old son that he had given to her on Mother's Day 1997. She read it with much passion and emphasis which left the group feeling emotional as they related their own experiences, some similar and some hurtful through an omission of any such gift on similar occasions. Linda remarked that these simple pleasures were the reasons why she had not given up the fight, even enduring the pains and uncertainties of "chemo".

Linda mentioned her ongoing struggles and distress with her 17 year old daughter, Natasha ("Tash") who throws tantrums if she cannot get her own way. The other women were all mothers so the advice and questions flowed thick and fast. When that had been exhausted, Linda continued to say that Tash had attempted suicide twice with an overdose of pills. She reported treading very carefully with her daughter in case she tried again. She has suggested therapy but Tash refused to go. The group members related their own experiences of attempted-suicide and recommended "Tough Love" support groups so that Linda could cope. She said she would make enquiries. She would also consult her church. Linda mentioned that she was confused with the behaviour of Tash as she is normally such a help around the house and reasonably cheerful with it. Tash was also one family member in whom Linda had not confided about her cancer, and Linda felt that "perceptive that she is, she may suspect that I am hiding something from her" and sought attention as a result. At the next meeting she reported that Tash had agreed to see the family doctor with her mother and that she had attended one session. The group were very concerned and showed it, between

meetings, by frequently making telephone contact with Linda at work as she did not have a home telephone.

In early March, Linda's support group began to have new meaning for her. Two new members joined the Thursday meetings and their effect on her was noticeable. For the first time in the group she shed tears when introducing herself to the two new patients who wanted to know, and pushed for, more details about Linda's situation. All her problems came pouring out as if that was what she had been waiting for. She listened attentively to others' ways of relaxing and finding stimulation (with activities such as painting, pottery and walking) to take their minds off their cancers while not losing the reality of their disease. She learnt how others managed to keep friends at bay or close, whichever one chose and felt comfortable with at a particular time. Linda reported in her homework ("ek voel meer gesond": translated to "I feel better") that this previous discussion had given her back a sense of control over herself which she then realised she had surrendered to the cancer since her diagnosis. She reported feeling much happier and walking around to see her friends not afraid of their questions about "my siekte of enigtiets" and with the intention of being open and honest. The group was full of admiration at such courage.

Linda then wanted to know about diets. She had read in a magazine about certain foods bolstering one's immune system. She was extremely hopeful that the new diet would improve her quality of life while still allowing her the occasional cigarette. The oncologist was consulted and shown the magazine article. He pointed out that these dietary suggestions were not for people who already had cancer. As a result, Linda was given specially prepared notes by the medical staff on dietary do's and do nots for her particular case, which led to the support group members present asking for the dietary sheets for their particular cases. Linda reported in her homework sheet feeling that she had contributed something to the group even though it was through an error on her part. The group learnt a great deal with this experience as others had read articles in newspapers and magazines and seen "something on telly" which went very close to saying that some new, wonder drug, root or diet was a "cure" for cancer. The

specialist warned the patients not to succumb to this, as it only led to hopes being raised and then dashed. Rather, he said, "listen to your bodies" when it comes to food and sleeping habits. There was no harm in being aware of bodily needs but before swallowing (literally and figuratively) anything, consult with one's oncologist who will treat the person and that particular cancer in an individual manner. Although the group learnt that no two persons' cancers are exactly alike, there is much common ground on which to "compare notes".

Linda contracted 'flu in early April. She recovered in seven days and seemed happy to have got over it so rapidly. Normally, she maintained, it remained in her chest an extra week, turning into bronchitis. At this stage, Linda remarked how her memory and thought processes in general had slowed down. Another patient in the group with breast cancer and one mastectomy reported the same thing but that it had improved three months after cessation of treatment. Linda was relieved at this reassuring news as her job with the bank required her to think and calculate rapidly. She reported that she had become absent-minded and would occasionally wander around and forget what she had meant to do. All the group members had experienced this during treatment and she reported feeling more relaxed when she realised she was not the only one. The same applied to her fingernail problems (not growing properly; coming off and then hardly growing again); they were causing a great deal of distress but when she heard others in the group having the same problem and then discovering that it was a common side-effect of her "chemo" and would return to normal later. This left her with a smile at "some of the silly things I worry about" (Linda's words). Everyone present laughed at her sharing with the group that she dyed ("still does", she said) her hair black then because when she was receiving "chemo" and all her hair fell out, she bought a black wig, so she had to stay that way for family and friends at that moment.

The subject of honesty began to pervade the group discussions. Linda likened it to pregnancy: you either were or you were not. This appeared to empower the group. They realised that this total honesty, coupled with their new-found, practised ability to say "no" when they felt it was necessary and the concept of regarding their cancer as

an opportunity to change distressful circumstances in their lives towards living a more conscience-driven life, would result in a healthier immune system. Linda spoke about her denial of reality and how this just added more stress to her burden; often forgetting to whom she had told what.

It was evident that this lengthy discussion of honesty with self, God and others had changed and re-opened blocked lines of communication. The group reported that the "truth" attitude began to infiltrate into various spheres of their lives; at work, with friends and playing sport (one member recorded in homework that she found lying to others led to hating herself even if she thought that the truth would have hurt).

Another aspect of honesty arose in attempting to clear one's conscience. When actively seeking forgiveness through Christ for what they had done in the past, the group members acknowledged that they would first have to forgive the wrongs/crimes/sins done to them. Linda initiated a discussion on forgiveness and holding a grudge which led to a debate on what to do with suppressed anger. The questions arose whether one should keep it in and how to release it with minimal damage for all concerned. Much knowledge was shared and gleaned by all present. The facilitator then gave a brief summary at the conclusion of two hours (a slightly extended session), trying to tie up the loose ends. Homework themes centred on learning to forgive oneself even after asking for divine forgiveness. As one member said, there could never be effective forgiveness without "wiping clean the slate".

In the middle of April Linda spoke about her pains. It was felt by the other members that she had already come out of her shell, while this topic served to confirm it. She went into great detail about the pain in her arm. The facilitator assured her that if it worsened an appointment would be made to see the oncologist at the next meeting. She made a commitment to report back any further pains; the group insisted that she keep her word, and asked her to try to cut down further on her smoking, but, on the other hand, praised her for her openness and determination to make healthy changes in her life.

After Three Months Participation

After three months of support group participation, Linda reported being happier, being able to smile more readily and more genuinely, and feeling more in control of her life. This is in contradiction to her hassles and life events scales and suggests a defensive pattern in the group sessions.

Linda then shared with the group about experiencing more daily hassles and far fewer uplifting experiences in her life, compared to when she had first joined the group three months prior. She reported that a good shouting match with an unmentioned relation made her feel wonderful afterwards. In the middle of May, Linda described her pain to the group. It seemed to all present that she was experiencing more pain than she was admitting. The researcher immediately made an appointment for her to see the oncologist on duty who examined her while the group proceeded. She returned much later to retrieve her handbag and informed the group that the doctor was sending her for a sonar X-ray at the hospital. The group accompanied her as she seemed a little scared and uncertain about where to go. The results of the exploration revealed nothing serious, much to the patient's delight and the group's collective relief. The doctor prescribed a course of treatment which led to a reasonably rapid recovery.

The 21st May was Linda's birthday and as it was also a Thursday she celebrated with the support group. After the session, she asked the facilitator if she could have "a few words" alone with him. She began very slowly by saying she had something she needed to talk about. She appeared near to tears. Then she said that her 18 year old daughter, Tash, had given birth to a daughter, Tamlin three years previously. Her parents and close family had not received the news at all well and told Linda it was a "disgrace". They did nothing to help during the pregnancy and refused to acknowledge the baby's existence. The unhappiness had wide-ranging repercussions. A once closely-knit family became torn apart. Linda had hung on to this "shame" (a translation) for three years and felt it was the time to talk to someone about it. She blamed herself

and so did her family. However, the child, affectionately known as Moo, had become the apple of her grandmother's eye. She then invited the researcher to Moo's birthday tea-party on the 26th May. The happy event took place and Linda appeared relieved that she had managed to get so much baggage off her chest, without more people sitting in judgement of her, her daughter and her grand-daughter. She reported feeling stronger after the party and more capable of coping with relations' opinions. She asked for a little time before she told the rest of the group as she felt that she did not want to spoil the relationships she had recently built up within the group. She remarked that being able to talk about this issue gave her a new sense of control over other issues in her life.

At the end of May, during a group discussion on how one's faith in the Lord Jesus Christ gave, even cancer patients, a great sense of peace and hopefulness, Linda asked what the group would do if a Muslim patient was to join them. This had been worrying her as she sensed that the group as a whole had made encouraging progress along the road of recovery. While Christianity had become such a source of comfort for other group members, it would be upsetting if a new patient's religious beliefs put the process on hold. The group decided, after a long discussion, that no cancer patient could be rejected on any grounds, especially those of faith. As long as there was respect for what others believed, then the discussions would not be compromised; perhaps, even stimulated. There seemed to be a fear of succumbing to new ideas concerning the Creator but the majority in the group felt that it would be a good test of one's own faith and good practice to listen to another's religious beliefs without, necessarily, being swayed in that direction. Linda had touched on a crucial topic and the conversation brought out a great deal of insight from individual experiences. The group looked forward to meeting such a challenge.

In the middle of June, the group met Tash. Linda had brought her along as she was in the city looking for a job and had gone to see her mother at work. The group was a little surprised that she was actually in the same room as the patients, but because Linda felt better with this arrangement, as opposed to her waiting in the reception area

of the clinic for nearly two hours, she was accepted although not encouraged to join any conversations. Linda appeared distressed. Tash, after half an hour, kept looking at her watch and unsettling the whole group. Linda spoke about pain; her own physical psychological and social pain. Tash, the group had previously been told, refused to accept her mother's "siekte" and still rejected the idea of her mother having cancer. Linda let her know, with the support of the group, exactly what she was going through and had been going through over the previous two years. She showed no reaction and, inspired by the group support, Linda poured out the truth of what she had endured in the past years. Linda held nothing back. This had the effect on the group of an open discussion on honesty, how dishonesty over time leads to distress and how this all may lead to immune system malfunction. Linda reported back later that the session had served as a real clearing of the air at home.

On the 18th June Linda had to rush home from work as Natasha had again attempted suicide. The researcher heard later from Linda that she saw Tamlin's father as the root problem in all her attempts. He was as determined to take her away from Natasha as she was to keep her. He continuously harrassed the family with late-night visits and threats of violence. A restraining order had been ignored for over two years and the high court was involved for contempt of court. She had been discovered in time and rushed to hospital where Linda eventually went to be at her bedside. Her daughter recovered but this had occurred at a time when another group member, Millicent, of whom Linda had become extremely fond, (as had the whole group) was admitted to hospital with severe complications of her cancer. This served to compound Linda's grief but she talked, between her tears, about all the grief pent up inside her. The group members began visiting Millicent in hospital, individually and together, and the support was evident; encouraging Millicent to keep fighting and to keep her faith, while she encouraged her fellow-members to be strong for her.

In early July, Linda made a new friend in the group. Thandekile had joined the group with recently-diagnosed Hodgkins lymphoma and the two seemed to "click" immediately. Linda reported that it was just what she needed emotionally. She told Thandi a great

deal about herself and it was reciprocated, which resulted in Linda at last, beginning to smile again. In mid-July she told the group that her next check-up was in a month's time and if she had to have chemotherapy again, she would refuse. The group responded by reminding her how fortunate she was to be having treatment made available to her by specialists while there are South Africans with cancer who are not being offered treatment because, due to social circumstances, no diagnosis had been made. Linda remained adamant: "no more chemo. ever again". The pain of this treatment had lasted too long and got progressively worse on each occasion. She received no sympathy from the group, as the members quite clearly stated they were not there to support such stupidity. Linda remained adamant and said she may visit a naturopath she knew. [An Update on her test results: the oncologist is pleased with her condition at the moment and no chemotherapy was necessary].

At the end of July, Linda reported significant success at work and that her boss had complemented her on her efforts. This was seen as very positive by the group, considering all she had been through at that time. She shared her happiness with the group in her usual, slightly shy manner. The relationships with her colleagues at work were a source of much upliftment. She also reported her appetite had returned and she was less worried about her diet, trusting her body sufficiently to "send signals"(a translation) when some food-stuff was not healthy. She shared with the group her feeling that the worst of the cancer was over and that she felt much more in control of her body and her life. She felt more self-assured of late, and practiced her total honesty by saying "no" when she meant it while not being open to negotiation on the particular issue. She admitted still being a little worried about the side effects of her treatment (especially the itchiness after the mastectomy and ensuing treatment) but thought of it less often. This affected the group members as they were concerned that she was denying the prospect of chemotherapy which may be necessary in the future. It was recorded in the homework that with her changes in her life, she was still not being completely honest with herself. One homework sheet mentioned: "If she cannot be honest with herself, how can she be honest with us". When the issue was raised at the next meeting, she responded by saying that she found herself so aware of her immune

system's state of health through all the information she had learnt from the group about what could undermine her state of health. She felt that having more treatment was not her constant focus of attention like it used to be. Instead, she preferred to get on with her daily life without being overwhelmed with worry.

This is one case where a woman in her forties with breast cancer which resulted in two mastectomies, was introduced to a psychosocial intervention two years after her initial diagnosis. She was slow to adapt to the openness of her fellow group members. She had many situations in her daily life, on joining the group, that caused her distress and many which had accumulated over the previous ten years. When she realised that she was not alone in fighting her disease and met people in a similar predicament who were prepared to give her unconditional support, she began assuming control of her life. She then found herself in the position of being able to reciprocate the support she had received. She attended over twenty meetings in six months.

Case Study 3: Maurice

Vignette 3

Maurice (also known as "frenchie") is a 57 year old, white, married man with two sons in their twenties. He is of French origin but now a naturalised South African who feels comfortable when speaking English and has an understanding of Afrikaans. He is retired after working as an artisan for Iscor, and now owns two shops in Pretoria which market cellular telephones. His youngest son manages one of the shops while Maurice trains him with a view to being a full partner in the family business. He reports a family history of cancer and the fact that his eighty-year old father was on his death-bed in Paris when the group began in February.

Maurice was diagnosed with cancer of the pancreas in November 1997. At first the disease presented as jaundice with all the concomitant symptoms, but on further exploration the cancerous mass was discovered. He was immediately put on a course of radiotherapy to control the disease which was later combined with a course of chemotherapy. Maurice was told that the prognosis for this type of cancer was poor; only about three percent of patients survive into remission. He refused to accept this and vowed to "keep fighting-it's in my nature". Before the diagnosis, he reported a reasonably healthy life-style and an awareness of dietary do's and do nots.

He reports not having money worries and has a useful medical-aid "arrangement" coupled with an insurance policy for his family. Although concerned about "death", his Catholic belief in a better life after death means that there is no reason to worry, he would rather focus on making provision for his family. Fortunately, the policies he has, were taken out long before the "diagnostic" (his expression). He explained that insurance companies load their policies' monthly premiums if they do cover the cancer patient. Many companies do not offer policies as cancer is regarded as a dread disease.

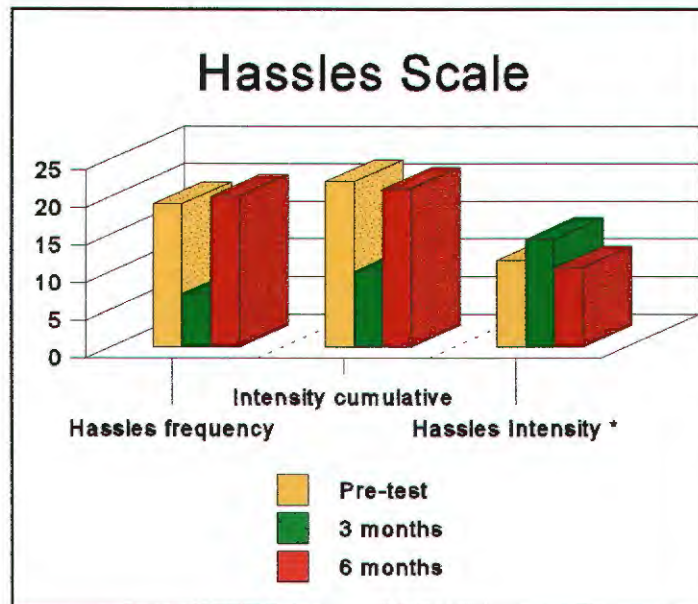
Scale Results (see Diagram 3)

When Maurice had completed the pre-test questionnaires, his scores on the Life events scale showed an even distribution of positive and negative scores for the previous ten years, including the current year. Most of the items evoked a moderately strong response whether positive or negative and this accounts for the low accumulated score (+3) and very low Intensity (0,21). In the discussion at the first interview, he reported feeling distress when moving to a new house and being irritated by the neighbours' inconsiderate noisiness, his eldest son leaving home and a recent court action.

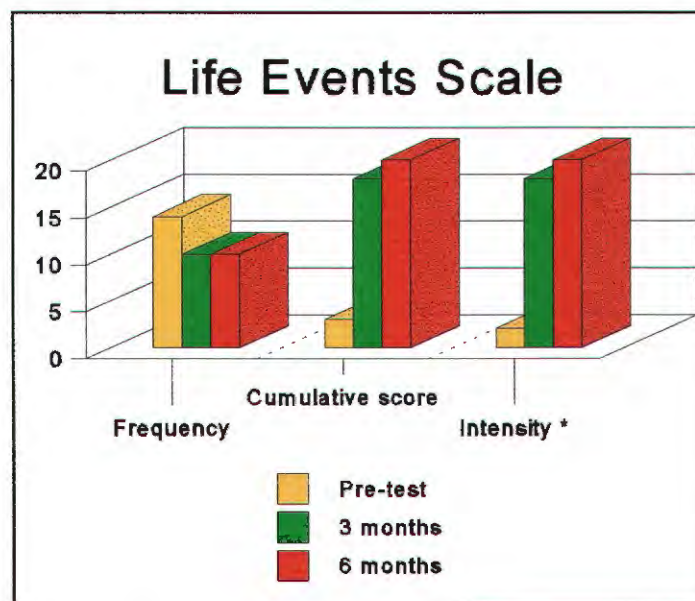
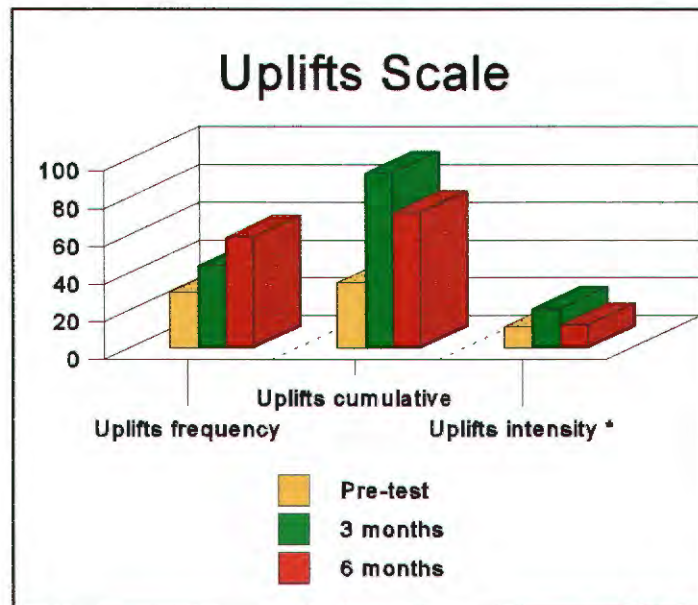
The Hassles scale administered at the first interview with the researcher, highlighted mostly concerns about his own physical situation, his family's future and his forced inactivity. The Uplifts scale revealed moderate scores for an equally, moderate amount of areas which led to satisfaction and which may explain the low intensity shown on the graph.

At the end of April, he reported recognising more areas in his life which made him feel good about life, and with more intensity. He again completed the questionnaires as three months had lapsed since the pre-test and the results were encouraging. As is highlighted in the graph, his hassles had reduced to seven even though the cumulative score retained its degree of potency which accounted for the fractionally raised intensity. The Uplifts scale reported fourteen new areas of enjoyment for Maurice which was also reflected in the Life events scale. When he discussed this with the researcher he related his growing domestic pleasures and peace with his son at the shop to the point where he helped out occasionally on equal terms. He remarked that he kept feeling sadness and grief about his father on a daily basis. His relationship with his wife, he said, was better than it had been for a long time. He was writing notes to his son managing the shop pointing out previous areas of confrontation and requesting feedback which he received. The outcome appeared to be a friendlier, more mature and less stressful relationship.

DIAGRAM 3



Maurice
 * multiplied by 10
 for display
 purposes.



After six months of regular participation in the group, the researcher re-administered the questionnaires to Maurice. Although the amount of situations in which he experienced feeling hassled, rose to a similar level of six months previously, his Uplifts scale results indicate the highest frequency (59) of the six month period, which coincides with the extremely positive results of the Life events scale. Maurice later ascribed the score on the Hassle scale to growing concerns about his health and disappointment that he may not see any grand-children. He mentioned that his father dying still upset him when he had a spare moment to think about it. His high scores on the other scales he attributed to increasing happiness at home and at the shop. He mentioned that he sensed his family had begun to enjoy his company since his temper was under under "management" (Maurice).

Current Stressors and Supports

The First Three Months of Group Participation

The dilemma confronting Maurice, since even before his own diagnosis, was his father's declining health in Paris and whether to go to France and make his peace after a stormy relationship and say his farewells. His heart urged him to go, his mind told him that it was impractical financially as he could not say how long he would remain with his father, once there. Furthermore, he had a business to run and his sister was at the bedside to pass on messages by telephone. The diagnosis for Maurice in November 1997 did not serve to clarify matters for a decision either way. There appeared to be as many arguments for and against going one last time, but Maurice then had his own treatment to consider a priority. The latest news (before joining the support group) from his sister in Paris was that their father did not have much longer to live.

In early February, Maurice shared this dilemma of his father with the group. Tearfully, he presented the facts and the group empathised with instances of similar decisions they had been confronted with in their lives. This helped Maurice to reach the decision of putting his own health first and not to go to his father. At the meeting on 17th

February, he reported that his father was very near death. He thanked the group for their support and said that once he had made his decision to stay (which the group had also suggested) he felt very relieved. After all, he said: " I have only been given a three percent chance of recovery by one doctor, and told by another that this cancer is incurable even with chemotherapy and radiation" and that he must focus on his own struggle. The group thanked him for letting them into his life in such an honest manner.

He then told everyone present how his life had changed since his diagnosis and the start of his treatment. He used to "love" shopping and "now I hate it". He reported being impatient, short tempered and angry with other shoppers, whereas before he had been friendly and chatty to them especially in long queues. He then waited in the nearest Wimpy for his wife to do the shopping, instead of doing "something I hate". He mentioned that he has an explosive temper which he normally manages to keep under control. The group did not pursue this issue further, at that time.

He enjoys his present job selling cellular telephones as he meets new people every day and enjoys having conversations with all his customers. He felt that his life had been successful in many ways. However, when one son left home, the family had to move to a smaller house where he found the new neighbourhood too noisy and distressing as he had no control over the volume. A recent vacation helped greatly to restore his "balance" and he found that his wife also benefitted from the short break, so enhancing their relationship which had always been strong but nevertheless "in need of attention, from time to time".

Maurice told the group in early March that his father had died. He appeared less anxious and drew some strength from the fact that he had been in touch telephonically with his sister up until the end. Maurice, on this occasion, had brought with him a magazine article on "diets to enhance the immune system" which he emphasised had been a great help in preparing his daily intake with "an immune-friendly" focus. However, his and the group's enthusiasm was short-lived since when the researcher showed the article to one of the senior radiographers, who in turn showed it to the

radiation oncologist on duty, their responses were very negative. Nevertheless, the article resulted in the appropriate medical instructions and recommendations for dietary control of the cancer patient's particular irradiation site (eg. stomach, head and neck) being issued to each group member. The group had learnt to check everything through their specialist. Maurice was thanked by the rest of the group for getting many questions answered that to other members had remained unanswered because they were afraid to ask in case there would be a further set-back to their already altered lifestyles. This led to another problem that Maurice experienced with his cancer doctors.

He complained that he was not receiving answers to his direct questions about his condition. The group members reported having similar problems with their doctors. The facilitator pointed out that, in his experience, the doctors could only respond on the presenting evidence based on their experience. They could not tell the patient how the cancer was going to respond to treatment in the future. There were too many idiosyncratic variables that were peculiar to each patient which prevented any prediction. Moreover, it would be unethical to give the patient false hope. Only the truth mattered, it was decided by the rest of the group, even if the doctor said that he did not know. Maurice saw this discussion in a favourable light as he began to see his doctors' perspectives while not being in any way inhibited from asking further relevant questions should the need arise. In this way, which induced much laughter from the other members present, he was a good example for establishing and maintaining open and honest lines of communication with all medical staff. The other members often complained in the group meetings of aches and pains before, during and after their treatments, but did not want to "waste doctor's time, he's always so busy" (a comment from a member's homework sheet).

Once it became apparent that this was a common problem the group made a decision: all such pain would immediately be reported to the doctor as he could not treat that which he did not know about. One of the group members, Pieter, was experiencing a great deal of pain in his chest area at the time, so an appointment was made during the meeting for the patient to see the oncologist after the meeting ended. The group

reported feeling greatly assured by the immediate action in response to the episode.

At the end of March, Maurice and his wife went away for a week's holiday. On the 31st March, he was back looking rejuvenated and fresh. He had left the shop in the hands of his son and, as a token of trust (he said), had not telephoned him while he was away. The group also had a new arrival which had a very positive effect on everyone present. All the previous discussions themes and issues seemed to rush at the new man who, far from being overwhelmed, asked many relevant questions in response. Maurice told him about his own "incurable" disease but related how the treatment was controlling for any spread. Diets, worries and relationships were subjects under discussion and the group had acquired sufficient knowledge by that stage to be very helpful to the new member, even though his throat cancer was unique for the group. The others were able to cement their newly acquired coping skills (e.g., being more open and honest in communication and being more aware of what was healthy for one's immune system and what was not) by repeating how useful they had been in several recent situations.

At the group meeting in the middle of April, Maurice spoke about his anger and how it wore him out physically. He reported that when he sensed he was losing control in a particular situation, he would "explode" and began shouting at whoever he perceived to be the cause. Instances where this had happened recently were in traffic, at the shop or about the shop when in confrontation with his son and at home when his son was being stubborn. The group felt that this may be due to his perceived loss of control over his body with cancer, leading to him seeking retaliation. He said he had always had a quick temper but, lately, people had shouted back or had not done as he had instructed. This made his anger intensify and the aftershocks tended to last for longer than before. He was now aware of how distress could further compromise his already weakened immune system, so he asked the group for ideas on how to help him curb this ugly characteristic. The group wondered if suppressed anger was not worse than letting it all out. The facilitator had with him a recent journal article on how suppressed anger, in a short time, weakened the persons immune system in an accumulative manner till

the "last straw" situation, where a relatively minor stressor could result in boiling point and explosion being reached. The group suggested counting to ten, watching film comedies, walking and talking with someone he loved who would listen until he had everything off his chest, shedding emotional tears to cleanse his system somewhere private and writing it all down on paper. Maurice especially preferred the writing of a letter requesting a reply. His son who managed the shop (at this stage he had opened the other shop) would be the first recipient.

At this stage, he also began to look for areas in his life which made him smile or laugh most frequently. The discussion and the group's willingness to make suggestions from their own experiences helped Maurice as he saw the help as useful to the group in their own circumstances. This bi-directional feedback was evident as others related to "Frenchie's" short-temper being exacerbated since diagnosis. The discussion had also brought to light the importance of being in touch with real worries and their sources. He had taught the group a great deal with his frankness and displayed an urgency about making drastic decisions which lead to drastic changes in his lifestyle.

His honesty effected the other members. He still used the word "incurable" when referring to his cancer but his major concern between treatments was a reasonable quality of life for his family. The group, at times, were astounded at his quiet acceptance of his prognosis but they never underestimated his fighting spirit as in one homework sheet from a new member, Attie, a word used to describe him was "fighter".

He later told the group he felt much healthier. He found himself less irritable with events in his daily life. Part of his honesty included the word "no" and meaning it, which relieved him of annoying social obligations ("some, anyway") which previously he had attended to keep others happy.

His Catholic faith ("fait") helped him feel that he was neither alone nor helpless in his determined efforts to recover. He felt an opportunity (the researcher suggested that it was a blessing and he agreed) arose from his disease in that it gave him an opportunity

to slow down and concentrate his energies on ordering his priorities in his life. Putting God at number one with his health thereafter meant he stopped being preoccupied with the future and concentrated on the here and now. Maurice continued to facilitate openness among the other group members and helped to reduce any fear that new members might have about asking doctors crucial questions about their state of health. He encouraged by example and often contacted members of the group during the week between meetings "just to talk" but most often to lift any flagging spirits. This was borne out by the others' homework reports and other feedback.

At this time he also lent his support to keeping the group's numbers down to less than six to give each person room to say what he needed to. He maintained that a larger group would lead to some never having a chance to address the group about their situation. He pushed for the ladies' group (Thursdays) to join the men at least once a month to meet and swap experiences. He was democratically outvoted by both groups but was reassured that he would meet "the Thursday ladies" at the end-of-year Christmas party. The reasons given by both groups revolved around feeling seriously inhibited talking about some of the side-effects of different cancers and their treatments. On many occasions, the person's sexual functioning was totally neutralised by various factors including the cancer treatment, with wide ranging psychosocially distressing outcomes. The debate continued a-pace, with neither group prepared to budge.

After Three Months Participation

In early May, Maurice's son (who ran the shop) married and departed on a short honeymoon. Maurice, who had done most of the organising for the wedding (much to his chagrin that the bride's parents had not offered to help), then had to tend shop in his absence. He reported that he thoroughly enjoyed it. He also told the group that his latest readings on cancer and its treatment had included a recent article in Time magazine about a possible cure. A week later the same magazine had published a retraction, indicating that there was still no conclusive proof of the latest discovery's effectiveness but that it was perhaps a useful supplement to medical treatment, as had

been shark fin cartilage, extract of potato root and even snails. Maurice's quest for the latest information raised another aspect of support group effectiveness: why not get more than one person in the group with the same diagnosis? This topic gained much support at first. However, it was pointed out by the researcher that even if that took place, cancer being such an individualistic disease, the two patients with the same diagnosis would discover as many differences as similarities. Furthermore, in any cancer diagnosis there is substantial common ground when the focus concentrates on psychosocial distress and immune function. There was a great deal more to be learnt from, and shared with fellow patients, concerning this aspect of the disease. It was agreed, eventually, that comparing medical notes of a person with a similar diagnosis would lead to more confusion than clarity. Besides, the overall knowledge of the medical side of the disease was definitely not the "department" of the support group. It was agreed that the group would leave that to the professionals who had already stated their willingness to the members to answer any medical questions when invited to attend the meeting as a guest.

Maurice then asked whether the drastic changes patients had made to their lives during treatment, applied should the cancer go into remission. He further pointed out that, taking one's immune system into account during treatment, it was demanded of the patient that drastic changes and sacrifices had to be made in their lifestyles as had been discussed in the group. The consensus within the group was affirmative. Maurice, towards the end of May, mentioned these sacrifices such as "careful eating habits where you listen to your body ... it will very soon tell you if something you want to eat is not right", much less sexual activity and a change in personality that cancer treatment can, and often did, bring about. The group members reminded him that remission did not mean a cure, merely that the medical team had the particular cancer under control and further treatment was not required at that moment. The discussion moved on to the subject of relapse, which is always a reality after remission has occurred.

The subject of a patient's possible relapse led to a discussion of Christian faith in the Lord Jesus and what He represents in the Holy Trinity. An emotional sharing of

experiences ensued and the group explored the possibility that their respective cancers could turn out to be a blessing if they allowed themselves to learn from the opportunity and make amends to any previous damage in their lives. A few of the group members mentioned in their homework that there was no going back to a previous lifestyle and that the responsibilities of remission were a "cementing" of all the drastic changes one had made during treatment. Some members mentioned that although their faith was weak or "lazy", commented one, before their diagnosis that meeting with "strong believers" in the group had rekindled their own faith in the Lord.

At the end of May, Maurice brought a magazine to the group in which an article covered the latest scientific discoveries on the road towards a cure for cancer. The article contained a thorough assessment of what had been presented, by the vice-president of the Cancer Association of South Africa (CANSA), Doctor Georges de Muelenaere, who summed up this new finding as "another brick in the wall" (direct quote, YOU magazine 1998) in the drive to fight the disease. The group felt re-assured that so much time, money and effort was continually being waged to find a lasting cure.

In early June, Maurice attended the session having just received his chemotherapy. He felt flushed and not at all tired. The researcher had brought the information that Maurice had requested about the latest research findings on pancreatic cancer from the university library. He was extremely happy to have more up-to-date knowledge about his cancer; he mentioned that it made him feel better equipped to have a conversation with his oncologists. He spoke about having more peace as he accumulated more knowledge and he understood more about his father's death from cancer and how it ate away his insides because his 83 year old immune system gave him nothing with which to fight. Knowing more led to greater relief with the newly acquired comprehension.

A new member in June gave the others an opportunity to reinforce their recent experiences and concomitant knowledge by talking about their new-found empathy. The members were cancer patients and, simultaneously, cancer counsellors. The

effect on the new member seemed to be very positive. The topic of who to blame for the cancer led to the subject of forgiveness. Maurice had had a bad experience with a priest who told him that his cancer was a punishment. The feeling from others in the group was that the priest had no right to say what he had; it could have been extremely detrimental to Maurice's attitude towards fighting his cancer. The incident did give the others an opportunity to explore the issues of "blameworthiness" and "forgiveness" regarding cancer. It led to a debate which concluded that the word "blame" has no place in a cancer patient's vocabulary. Dwelling in the past, looking for a possible cause when there were normally several contributory factors and filling one's life with regret would merely compound the seriousness of the psychosocial distress in the person and lead to further impairment of the immune system. The focus must rather be on the here and now. First, accept the diagnosis, then allow the, ideally, holistic (in the sense that running support groups in tandem with the medical treatment would indicate a shift towards a multi-disciplinary approach) treatment to take effect.

Maurice further encouraged the new member by discussing what he experienced during his own chemotherapy, such as having a J-line inserted in a vein to facilitate the drawing of blood to check the immune system's strength before receiving chemotherapy. This served to save a great deal of pain for the patient and suffering for the nursing staff. The ward sisters try so hard to find a suitable vein with as little discomfort to the patient as possible, and were often upset with themselves if they did not find such a vein at the first attempt. The new member reported the same experiences and related to the pain of needle-insertion not being initially successful. He said he would discuss a J-line with his doctor. Maurice reported feeling good that he had helped a new member at his first meeting. He also told the group that he had given the subject of new members a great deal of thought. He felt that he and the others who had been attending the meetings regularly since February had covered many topics concerning their own and other members' cancers. Rather than "bombarding" the new member with all this accumulated information, there had to be a better way that did not scare people away nor make the meetings boring for the "regulars". The group decided unanimously that in order to maintain the interest and enthusiasm of the

regulars while at the same time helping the new arrival to feel comfortable and gradually make friends in the confidentiality and safety of the "special" room, the new man should be encouraged to draw up a list of questions, in order of priority, which he needed answering concerning his cancer and related issues. This list would be brought to the following Tuesday meeting. His first contact with the group would focus on introductions and would include the others briefly giving him an insight into their personal lives and respective cancers with treatment details. The openness, honesty and sincerity of the regulars would, perhaps, encourage him to feel more at ease with "these strangers" and in time find some common ground. Maurice emphasised the importance of the new patient's list; it would give direction to the discussions and keep the focus on precisely what he needed to know. This would serve to encourage the members not to waffle as time at the meetings was precious, more so to the new man as he gradually acquired coping skills to manage his disease and the side-effects of treatment. In this regard, at the end of July, Maurice gave valuable assistance to a new member who was suffering from the accumulated after-effects of his particular chemotherapy. They shared experiences of how it affected the taste buds, leaving a "tinny" (Maurice) taste in the mouth, while the pain and the nausea prevailed for some days afterwards. Maurice found that if he drank ice-cold water immediately after his chemotherapy it kept the nausea and "tinny" taste away. He also shared with the group how he learnt a lesson about listening to his doctor. He had been given pills for pain and nausea after his chemotherapy and was told to take them on a regular basis. He decided not to take them until he felt pain or nausea. It turned out a terrible mistake, so he learnt the hard way. The new patient admitted doing the same, and making the same error: the pills are taken to prevent pain and nausea if taken in advance, not when the particular symptom arises.

Maurice reported back on his anger being under control and how he coped with it on a daily basis. Mainly writing and walking/talking with his wife, he claimed that their relationship then was better than ever before. He found the whole family were more relaxed with him as he explained: "somehow, there are no more seething, boiling rages". This may have been inter-related with the fact that his recent tests showed that

the treatment (chemo- and radio-therapy) was controlling the cancerous mass and there was no spreading. However, the planned course of treatment would continue until completion before a remission could be considered.

This is one case where a 57 year old man with pancreatic cancer, responded well to a psychosocial intervention while receiving medical treatment. Although the patient had a minimal chance of recovery, he fought to prove the statistics wrong. His personality showed many instances of determination and refusal to succumb while enduring the pain of treatment and uncertainty. He attended twenty one group meetings in the six month period.

Case Study 4: Janet

Vignette 4

Janet is a 54-year old, white, married, South African woman with two adult sons. She is the main breadwinner at home, as her husband, a land surveyor, chooses not to work.

Janet mentioned a very lonely feeling at home and a cold, distant relationship with her husband which has been the situation for some 15 years and there is little or no communication between the two. The situation is always tense. She has worked in the food tasting business for twenty years in South Africa and now has her own business in Midrand, Gauteng. She lives in Pretoria in a home that she redesigned herself and drives to work every day. She knows that her family has a history of cancer but has not investigated how many generations it goes back. Janet was diagnosed with one of the leukaemias, multiple myeloma in late 1997. Myeloma is specifically a malignancy of plasma cells which are produced by the bone marrow. Normally, division of cells takes place in an orderly, controlled manner but with myeloma the process gets out of control. Abnormal plasma cells multiply too rapidly, producing many myeloma cells. These fill up the bone marrow space and suppress the normal cell production, which may drastically disturb body functions. The disease represents roughly five percent of the total number of malignancies reported (Pervan et al., 1995, p. 514).

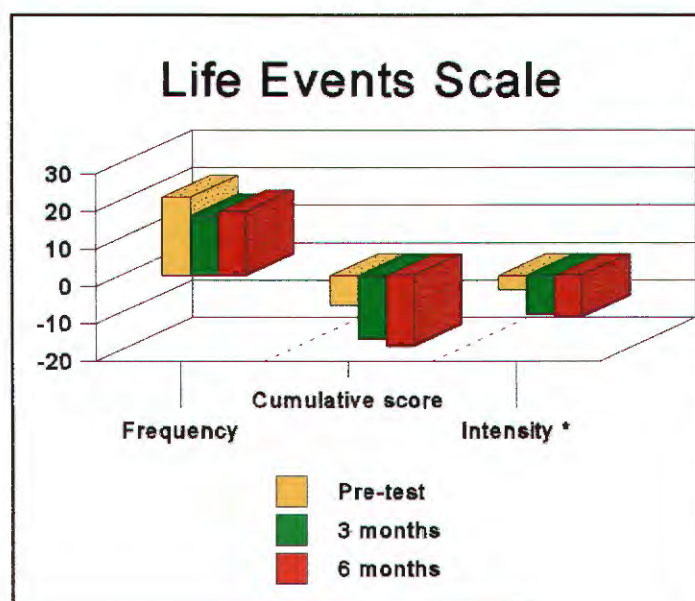
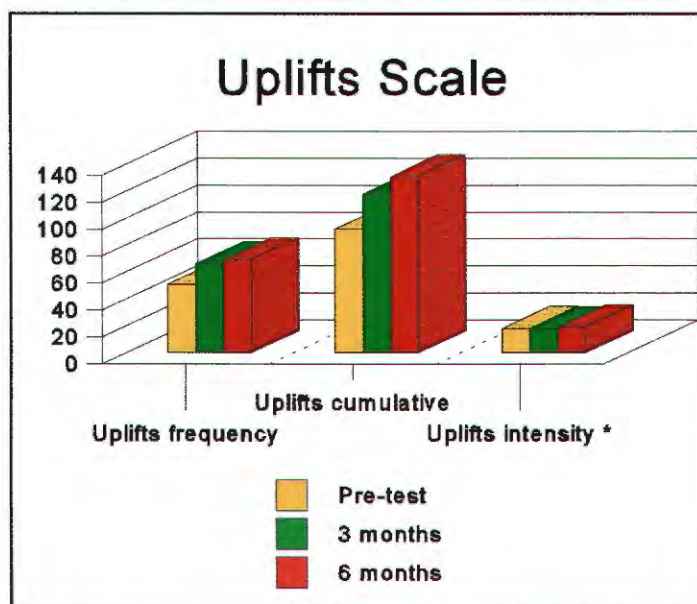
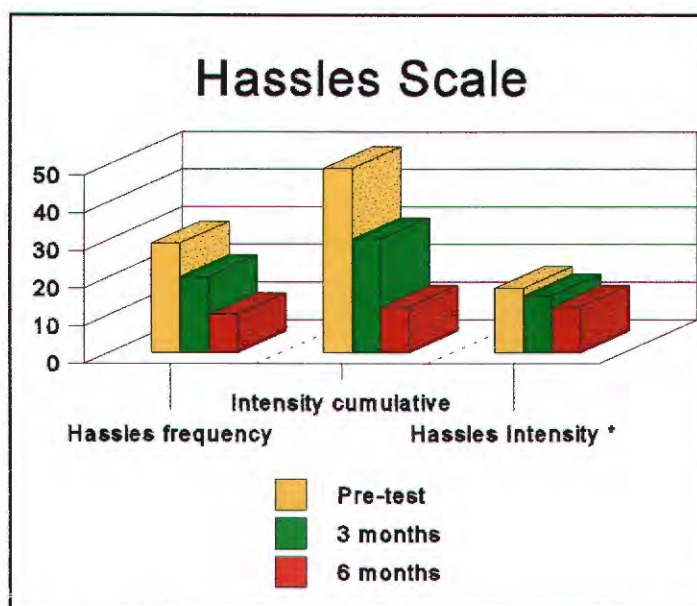
Scale Results (see Diagram 4)

At the initial interview with the researcher, Janet showed a very positive nature interacting with a great deal of negativity in her life. The results of the Life events scale followed exactly the same pattern. In the 21 items marked as applicable to her life, her cumulative score of -8 comprised of -29 and +21 scores, which led to an intensity of -0,38. Her Hassles and Uplifts scales depict much of the loneliness and heartache in

DIAGRAM 4

Janet

* multiplied by 10
for display
purposes.



one area being offset by a zealous determination to find happiness and, therefore, balance in others. Unfortunately, her attempts at over-working in order to shut out the domestic misery failed and perhaps contributed to her present state of health. In the ensuing discussion in early March, she put forward the reason that she was too busy providing for her family and running a new business to take time off to do the things she needed to do. She told the researcher that her clients were very demanding and expected the best service from her because that was how she treated them in the past and now they were used to it, they "demanded nothing less than the best". Since other people always came first in Janet's life, in fact were her top priority, when she was diagnosed with leukaemia and had to take "time out" from work and spend more time at home, this became the source of great anxiety, crisis and depression. She reported feeling more worried about her customers than her own health as she knew she would triumph over "this minor setback". Then she discovered that she could not talk to anyone about her cancer and that no-one she knew seemed to care enough to ask her about her disease (she knew that some friends did know about her, she said: "bad news" but preferred to stay away from her in reaction).

At the end of May, Janet again completed her questionnaires. Her Life events results indicated a more negative cumulative score and a more negative intensity than had been the case three months previously. The inconsistencies that exist in the Life events responses tend to indicate that there may have been occasions during the group sessions that her positive verbalisations were a form of defence to shut out further exploration through questions by other group members.

The Hassles scale, however, revealed a slight reduction in her daily problems and a concomitant lowering of intensity. The Uplifts scale supported this as it exposed 15 more items where Janet reported growing happiness. In the ensuing discussion, she mentioned that all her old problems at home remained with her. She claimed they were unsurmountable and unchangeable which just added more distress. These, she said, were life events always putting her under pressure on a daily basis and she had reported the other scales as more immediate issues (within the last month, as required

by the questionnaires). She mentioned that she gained much joy from talking to her friends and even complete strangers about "her group" (her feedback) and how she was enjoying most of the topics.

After five months of group participation where Janet had only been absent on five occasions, therefore attending 15 sessions, the researcher asked her to complete the questionnaires as part of the post-test data. Her responses, apart from a slight reduction of areas which led to irritation (hassles) and a fractional increase in the number of situations where she experienced upliftment such as her support group sessions, revealed little difference to her test scores three months prior.

Current Stressors and Support

The First Three Months of Group Participation

On 5th March, Janet attended her first support group meeting. Her immediate openness about her private life and its history of upheaval in great detail, at first led to silence from the others. They reported in their homework that they just could not take it in that this outwardly "jet setter" and "go getter" (extracts from homework), could inwardly have had the same problems and even catastrophies that they had. The silence led to tears from the others and a slow unravelling of their related problems which led to a discussion on learning to relax. The group shared their own styles of relaxing in detail, all the time trying to show Janet that she was not alone in her depression and loneliness. Aromatherapy, hiking, comedy theatre and having a facial were recommended as having worked for a patient's pain and misery. The group touched on finding any stimulation to take their minds off their cancer and this led to a lively discussion on whether too much "taking one's mind off the cancer" might lead to denying its presence. The counter-argument centered on a balance of always being aware of one's disease but finding external stimulation so as to bring some laughter and joy to the serious situation. The subject of friends was raised by Janet and she highlighted her need to at least feel in control of her space when friends made their

demands. The others agreed that keeping friends at bay, then having them close and then keeping them at bay again, takes training. The subject of saying “no” when one’s conscience required it and not negotiating the issue with anyone, including friends (Janet said “especially friends”) was something one was forced to do if one had cancer. The treatment, she said, even the knowledge of having cancer, often left one feeling “out of sorts with others and life in general” (her words), and putting one’s health and determination to recover first on one’s list of priorities was surely healthier for one’s immune function.

A group member (Annaljie) then responded that on top of the list of priorities must come a spiritual intervention from the Lord Jesus Christ, the Son of God. All other priorities would then be managed within that relationship of faith and trust. The meeting ended with a unanimous call for a continuation of that subject at the following meeting. The homework report-backs also confirmed this interest and Janet appeared to have stimulated a fruitful discussion on how to be part of the road to any lasting recovery for cancer patients.

At the following week’s meeting, a member brought up the subject of her spouse’s refusal to communicate in any way about her cancer, even though he had cancer himself. The group members responded by suggesting that she rather accept him the way he is and stop fighting as this would only lead to more distress. It was mentioned that it also caused her husband stress when he saw her negative reactions if he did not conform to her expectations. This led Janet to suggest that the group members should stop trying to do everything on their own. She suggested that they rather accept that some things in daily living, which some found distressful, were unalterable without “divine intervention” (her words). Problems with communication between spouses required expert intervention, so it was agreed that the proven expert in all earthly matters, God, would be called on to intercede through prayer. This approach would then reduce a great deal of distress as the problem was then in the Lord’s hands. Janet mentioned that if one was to believe what she had frequently heard before that: “God helps those who help themselves” then where, she asked, was one’s faith. She

mentioned that she knew that faith was an all or nothing belief in Jesus as the Son of God and the Saviour of all sinners and that He did not want to be involved with only selected parts of His children's daily problems, he wanted the whole problem or nothing at all. The group meeting went on in this vein until after four pm on this occasion; an extended but fruitful session. The homework indicated that the discussion had sparked off much soul-searching in the week that followed.

The next session in March, focused on the human immune function as members had seen a TV programme where it had been discussed in depth. The researcher was asked for more information (in layman's terms) which was provided. How did one restore one's immune system back to health after it had endured so much during the cancer process? was one of the following questions. The group needed more knowledge and this was again provided via the researcher's university library at the following meeting.

Janet, by the end of March, was admired, loved and cared for by the whole group. The emotions were mutual. She spoke with wisdom, compassion and depth of understanding while the members seldom interrupted as they gained new insights, not only about themselves. When others spoke from their hearts, she listened attentively as if nothing else, and no-one else, mattered. Her intimate revelations (e.g., "I need to feel like a woman again") had a snowball effect on the other members who, with their new-found confidence, gave vent to their own suppressed truths. When these emerged, they were approached with empathy, never sympathy.

When the matter of loneliness arose, Janet spoke earnestly. Cancer was a very lonely disease. When one was with family, friends, medical staff and even priests there was no-one to talk to who remotely understood about the hopelessness and dreaded depths of the pain that accompanied diagnosis. One feared, she mentioned, the uncertainty of specialists not knowing exactly what was going to happen during "your particular course of treatment". From being the most gregarious person in her world, she had nobody that she wanted or dared to be with or even talk to. The members were

stunned but full of advice. She hushed them when she said that, that had been before the realisation of the cancer had sunk in and she had "turned it all over to her Lord". Within a few weeks she had found a fellow-patient support group close to where she lived.

She had taken the group through a decade of her life before coming to Jesus. From loneliness, even in a crowded room, exacerbated when she received the news of her diagnosis and then, an answer to her prayers, she had all the support she needed. Even being on her own after that, was the "furthest thing from loneliness". The group responded with much relief and enthusiasm, and told Janet that if it had worked for her, then her "remedy" could work for them.

In early April, the group discussed honesty and how this may help towards restoring one's immune system to a healthy condition. Janet found that when she had told a "white lie" in the past, it definitely had caused her momentary distress when her conscience had "kicked in". Another member suggested that honesty was like pregnancy; in that you either were or you were not; there was no middle ground". Furthermore, it was pointed out, that there were two types of lies; the act of actually telling a lie, and lying by omission. The group found this to cover all the ground required and suggested implementing it. [They asked the researcher to share the conversation with the men on the following Tuesday's group meeting]. The practice took the form of behaviour rehearsal. When an acquaintance one seldom saw, suddenly arrived on one's doorstep asking: "how are you?" and "let's go out to eat", how difficult was it to tell the truth? If one did not have cancer, one might say "fine" and "yes" but, having the disease demanded drastic decisions. The group rehearsed saying, "no, thank you, I have cancer and I am battling with the side-effects of treatment". Janet felt that having said "no" did not require any form of apology with it to soften the blow to the person on the receiving end, no matter how close the person's relationship. If he or she did not understand or like the word "no" that was not the patient's problem. A related topic arose concerning "listening to one's body". This was one of the important requirements during cancer treatment, especially if one suddenly felt tired. It was noted by all the

members that during treatment, especially chemotherapy, the body suddenly made demands; for example, tiredness, thirst, an urgent desire to eat something salty and the need to take deep breaths of fresh air. This led to Janet's suggestion that the group practiced being honest with themselves in their daily lives in order to build up the confidence to be honest with others. She further remarked that, that was merely an exercise in communicating with one's conscience. It meant getting into good habits through training and then sharing any new accomplishments during the following week, at the next meeting or over the telephone.

Another member shared her experience of recently forgiving someone against whom she had held a bitter "grudge" for many years. In order to do this, she recalled, she had to be painfully honest with herself as the burden was becoming too much to bear. Then suddenly feeling encouraged to confront this person, she re-told the truth behind the whole reason for the grudge and in forgiving was, in turn, forgiven. She felt as if her Lord had been involved all along and had forgiven her for holding on to the animosity for so long. Janet replied that such sincerity had been an example to every member. [The researcher carried this whole event over to the Tuesday men, where it was found to be very pertinent to their respective lives]. A lesson had been learnt as to how one could best cope with any bitter resentments, no matter how long they had remained buried. When the women heard the feedback of the positive response their discussion had, had on the men, they felt that the subject of total honesty and how putting it into practice, seemed to rejuvenate one's immune function through the lifting of previous unnecessary baggage from a previously compromised conscience. That, when relayed to the Tuesday group, served to facilitate the patients' further examination of their lives to see if there were other "unresolved/unforgiven" instances. On the subject of forgiveness, Janet reminded the group of the Lord's Prayer and the thought that "holding a grudge" against someone, precluded the person from asking the Lord for any forgiveness. This, she stressed, was part of honesty since searching one's heart for instances one had not forgiven another or oneself, required absolute honesty before there could be any divine forgiveness and restoration of a healthy balance in a person's life.

The following meeting in April, saw the start of a relationship (for Janet, especially) with a new member that had an overwhelming effect on all who met her. Millicent was a senior nursing sister at a city hospital who had recently been diagnosed with stomach cancer. She and Janet were "two peas in a pod" (another member reported in her homework) and immediately clicked especially on the subject of honesty and how the opposite causes a person a great deal of distress in the long- and short-term. Janet mentioned that in any relationship the essential ingredient has to be absolute honesty ("no matter what") or it would not survive. The group then discussed how that was especially the case when in a close relationship with God: "why would he listen to one of his children unless they were being 100% honest". Furthermore, His knowing what was in one's heart made it impossible to omit anything. He wanted to hear it all if He was to intervene and do any "divine repair work". The immune system, then, would no longer have to cope with the daily, compounding distress of a constantly, challenged conscience. It, under present circumstances, would be free to fight the cancer and cope with the side-effects of treatment. Listening to this discussion led to new members finally joining in the debate, and in retrospect, this issue became the foundation to involvement in the conversations held on other cancer-related topics.

In early May, Janet (after attending nine sessions) spoke about her needing to feel like a woman again. She complained that her husband was so cold towards her, and would not communicate except with silence. Their relationship stopped being "50/50" two decades previously. She mentioned that she wanted and needed to feel loved. The members responded that the support she received from the others focused on the love, caring and happiness she gave, and received in abundance, from the group as a whole. Each individual found themselves reciprocating in a sincere way, not just once a week but on an ongoing basis. This led to emotional thank you's from Janet and from other members, about what Janet had done and was doing for them in many ways. She mentioned that she had never experienced such genuine love and understanding. In her homework reportbacks, she iterated that the group had given her so much hope through their emotional support. The others, she related, had taught her to slow down and to listen. The continuous gift of friendship was an enormous blessing and made her

feel "years younger". She gave encouragement and at the same time learned the art of receiving thank you's, compliments and encouragement. She mentioned that she felt closer to the Lord, her Saviour, than ever before and began to see her disease as a blessing "without disguise" as the relationship strengthened on a daily basis. She told every one she knows how happy she was in the new relationship, and most replied with: "but have not you got cancer?" and then when she told them with whom she was having the relationship (with God), they were further stunned and said things like: "you never used to be like this, Jan". The others in the group enjoyed the fact that she brought a great deal of fun and laughter with her to the meetings "as if you have not a care in the world"(she was told). She replied that it was the group that had brought out the best in her.

After Three Months Participation

In early June, Janet reported that she had made more time to be with nature (such as walking in public gardens) over weekends and had slept better as a result. She woke feeling refreshed and regarded each new day as a blessing from "above" leaving her happier and with a new found vigour for putting as much as she could into the day. She made an effort to be open and honest (at times, brutally blunt) with those she met, and reported speaking up for her Lord Jesus as her personal Saviour, not only with regard to her cancer but "as a buddy for life". She also recalled having more energy each new day and hardly ever thought about tomorrow: "not my department" (her comment in reference to her faith in God). She had made more time at home to listen to her favourite music as it helped her relax somewhat. She remarked that the support group had created a new dimension in her life. She was coping better, she felt less stress attributed to sincere caring and she was feeling less lonely. When asked to consider the things that hassled her, she remarked that being able to talk and think rationally about them, had made them less "monstrous" (Janet's expression). She added that they did not seem so important any more and that she was really working on being in touch with, and thanking God for, her many blessings which had led to the creation of a better balance in her life. The subject of a better quality of life through

balance, stimulated and dominated much of the group's discussion for a few weeks. The focus remained on being in touch with nature when enduring the worst side-effects of treatment, as this put one closer to God the Creator. The peacefulness that the Lord promises his followers, leaves one aware that earthly worries are best resolved in a partnership with Jesus who has a plan for His devoted ones.

The next meeting in June centred on cancer-related pain. The group wanted the researcher to acquire more information from the medical library on pain and the immune system's role in onset, mediation of its duration and alleviation. The group members spoke about physical pain, psychological pain and even how socio-cultural factors (e.g., apartheid) lead to perceiving another person's pain which had led to great distress (perhaps through shame and guilt for not doing anything to alleviate another human's agony). Each group member related instances in their own lives where the pain they had experienced and witnessed had left them feeling totally drained, even to recall the circumstances had been distressing. However, when the members talked about these times, they reported a sense of relief when they discovered that others present had, had similar moments and similar emotional reactions. In fact, the homework after that particular session displayed a rich empathy for others' pain and a "putting into perspective" (an extract) of their own emotional reactions to their own painful moments in their lives, which appeared to have resulted in a perceived step-forward in understanding personal instances of grief. The researcher was reminded by Janet in her homework that pain one experiences as a cancer patient, hardly compares with the pain Jesus suffered on the cross when He was dying for our sins.

In the middle of June, the group held their meeting at the hospital bed of one of the members (Millicent), who had been admitted with complications to her cancer in the chest and stomach areas. She was having daily radiotherapy in these regions and she seemed happy at the group's presence. Seeing her reaction lifted the spirits of the other members considerably. Later at the same meeting, Janet had to have a scan for a new pain in her neck that she had reported to her oncologist, who saw her before and after the X-ray. The doctor reported no cause for alarm, and the group that had

accompanied Janet to the X-ray rooms, was as relieved as she was.

The next meeting welcomed two newly diagnosed patients and welcomed back a patient, Annatjie, who had been part of the group from the outset, but had, had to leave after 3 months participation as her father and a close friend were dying of cancer near where she lived. She informed the group, at that meeting, that both had died in the previous 2 months and that she needed some more support. Janet asked if she, too, could bring a friend with cancer even though she was not being treated at the clinic where the support group meetings were held. Once this had been given the go-ahead by the group, she told the group that her latest tests had showed that her myeloma was getting better but that the problem with the leukaemias was that they "lurked in the background" (her oncologist's words), she had been told. Nevertheless, the news of improvement delighted all present and gave immediate hope to the new arrivals, who then proceeded to introduce themselves to the group and vice versa. The meeting centred on discussing all the various types of cancer in the room. Further information was requested from the researcher on the individual diagnoses of the new members. The meeting, introductions over, became amiable as everyone began to relax and learn a little more about each other and discover any common ground for future discussions at subsequent meetings.

In the first week of July, the group again met at Millicent's hospital bed. She was heavily sedated and she had her family, priest and friends with her. Half an hour later, the group returned to their usual venue and discussed death and dying. The very special person the group had just been to visit, was visibly dying, yet was looking so peaceful and even smiling despite the morphine medication for her pains. The members then reflected on their dying and wondered if such peace and tranquility could be achieved. Some were frightened but Janet summed up the pervasive feeling in the room by quoting from a book she was reading: "the angels wait to take your soul back to its Origin", which left everyone breathless. The following week in July, Thandi arrived from Swaziland. She and Janet immediately "clicked" as if they were long lost friends. Thandi reported in her homework that she was immediately made to feel welcome by

all, but especially by Janet who managed to get her to open up and speak frankly about her particular cancer. She told the group how she had been diagnosed after her doctor had “side-stepped” telling her the results of her tests. She had then demanded to be scanned. Janet mentioned that she related to her zest for truth and the discussion then focused on how different cultures regard, and deal with, a disease. There proceeded much sharing of information and Janet had made a new friend feel relaxed from the start. She remarked how the truth can set one free to tackle the urgent task of recovery, and that Thandi’s quick acceptance of her cancer diagnosis and her willingness to “share herself” openly with the group, only bode well for the future.

At the end of July, Janet shared her grief with the group that she had recently lost two very close family friends in a motor accident. As the emotions surfaced and the tangible support flowed to the very person who had given others in the room so much support in their times of emotional need, Thandi began sharing about her recent tragic losses in Swaziland. It became even more emotional, yet cathartic, when the others recalled their losses and friend Millicent’s peace at her imminent departure to be with her Maker. Again, Janet set the example that everyone needed at the time, by facilitating being in touch with one’s emotions.

This is one case where an entrepreneur in her fifties was diagnosed with one of the leukaemias (multiple myeloma). She realised immediately after diagnosis that she needed to talk openly to people whose concern was unconditional. When she had joined the group in Pretoria she reciprocated on all the occasions she had drawn strength from the other group members. Janet attended 16 sessions in five months.

Case Study 5: Pieter

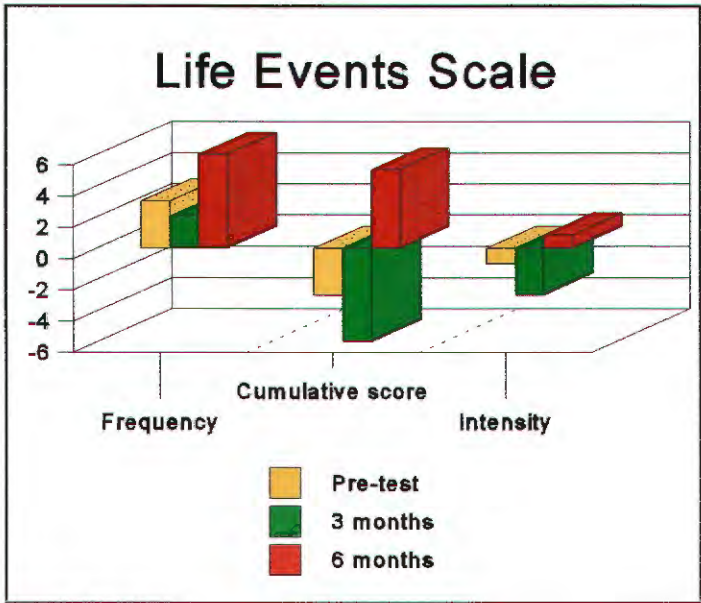
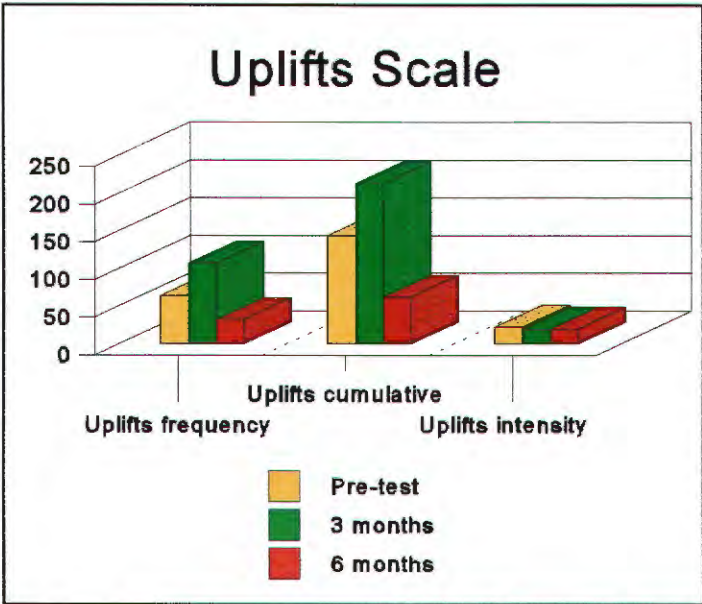
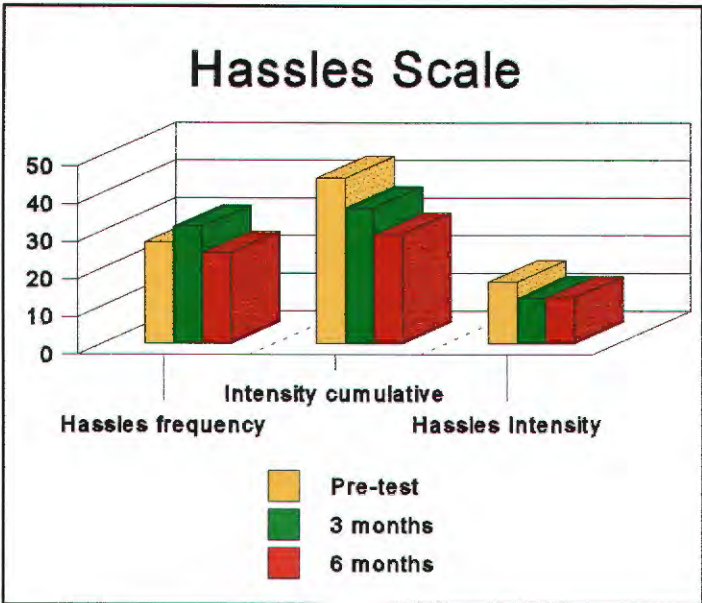
Vignette 5

Pieter is a 53-year old, Afrikaans-speaking, white South African who lives in a middle-class suburb of Johannesburg (JHB). He is married, has five sons and six grandchildren. The company he worked for (at present Pieter is on pension) provides an adequate medical-aid and pension scheme while he also reports few money worries. His family has a history of cancer amongst the males and Pieter admits to being a moderate smoker for the last 20 years. In January 1997, after reporting great pain in his chest and throat, he saw an oncologist and was diagnosed with lung cancer, the second most common cancer in South Africa. His condition required immediate surgery and a large amount of his right lung was removed before the cancer spread any further. Pieter was then treated with courses of chemo- and radio-therapy at the Muelmed clinic in Pretoria.

Scale Results (see Diagram 5)

The Life events scale which he completed at the initial interview, recorded three responses. The two extremely negative responses concerned his pet and his own health while the extremely positive response emanated from his finding a new job within his capabilities. These responses led to the negative cumulative score and intensity as shown in the graph.

The Hassles scale, however, revealed twenty seven other sources of distress in Pieter's life at that time, mostly concerning his condition per se and the negative perceptions he had about how his family were coping since the diagnosis. Pieter admitted confusion at having to confront this close-knitted circle with the news about his diagnosis and how the regular treatment after his surgery was going to change his lifestyle. He feared rejection because of the disease; not directly, but with people on whom he had previously relied for their support and friendship, avoiding him.



His Uplifts scale results showed the joy he derived from being with his family which often led to a favourite pastime of laughing. Apart from the death of his family's favourite pet dog in 1988, Pieter also mentioned in the interview, that he and his family always tried to look on the bright side of life and not let current events change their attitudes. He reported a strong, "tried and tested" support network of family and friends who usually closed ranks in times of hardship and distress. Feelings were normally only discussed within the family.

His main concern at that time in his life, appeared to centre on the well-being of his grand-children. He never gave up hope "no matter the obstacles" (his words) and certainly did not want his own worries and concerns to creep into the lives of his loved ones. He also recalled being distressed at having to wait to hear the results of medical tests that had been administered to him. The uncertainty, he found, was extremely frustrating. It was just another area where he had lost complete control over any outcome. He found that his memory was seriously failing him, where it had always been so reliable, making him angry and almost cynical about himself "losing it".

The researcher re-administered the questionnaires after Pieter had been a participant for three months. The most noticeable change came, surprisingly to the researcher given that he had spoken openly about his family worries, in a 50 percent increase in the amount of situations where Pieter experienced upliftment. Furthermore, he was enjoying previously reported uplifts much more. In the resultant discussion, Pieter told the researcher that he had always looked on the bright side when facing any upheaval in his life, and since he had accepted his diagnosis, he had felt a sense of relief; sufficient for him to start enjoying himself once more.

At the end of July, which was six months since Pieter had first joined the group, he mentioned to the researcher that his wife was bringing him into Pretoria for a check-up at the same clinic. He agreed to complete the questionnaires while he was there. The graphs indicate a substantial reduction in uplifts (from 107 three months previously to 32 then). These, he later reported telephonically, were due to his cancer overwhelming

him (it had by then spread to his left lung and more surgery was being seriously considered) and feeling the after-shock of his son's departure to Australia. He also mentioned that he missed the "commeraderie" of the support group. He reminded the researcher that he was soon to go and visit his son in Australia and that thought had inspired him to keep his spirits up.

Current Stressors and Supports

The First Three Months of Group Participation

Pieter, in the first week of February, mentioned that his lungs were giving him a great deal of pain and his throat was irritating, "like having a rash in there" (he said) and causing much discomfort when eating, drinking or even swallowing. Another group member suggested that he report this immediately to the cancer specialist but Pieter made light of it and said he would if the pains and throat problems did not improve very soon. The group were not happy that he should put off seeing the doctor as it was obvious to all present that it was causing him great distress: "That's what these meetings are for, Pieter"; said one of the group members, "to reduce distress in as many areas of one's life as possible".

Pieter quickly made a good friend in the group, Maurice, and the conversation shifted to their comparing notes about cancer related experiences to which the others enjoyed listening. It was noticeable, and this was confirmed through the homework of other members, that Pieter's new friendship and the fact that the group cared sufficiently for his state of health that they insisted he seek immediate attention from the specialist-doctor on duty, not only led to Pieter coming out of his shell (he had been sitting with his arms folded and appearing withdrawn at his first group meeting) at the meeting, but also set in motion the support potential of the group in response to an open and honest sharing of a matter causing distress to one of the patients.

In the middle of February, Pieter told the group that he had tried their suggestion that, to make up for his memory lapses at inconvenient times, he should place a piece of paper on his fridge door, keep a pencil within easy reach and jot down matters of importance. It worked efficiently and was re-assuring to just know it was there in case something happened on the way to or from the kitchen to distract him. Another new member reported similar irritating and sometimes embarrassing memory losses during his treatment phase for another type of cancer, and through much laughter, it was agreed that a problem shared was a problem halved.

In the homework feedback that followed, it was apparent from other members that the discussion and practical support had been a boost to their confidence and an inspiration to the raising of their own troubles, however trivial they may seem at first consideration. Another patient on the group found that going through a similar ordeal much more distressing, yet received strength from Pieter's raising the matter combined with how the matter was resolved. Pieter told the group about how much joy his grandchildren gave him. He said: "just to be in the same room". This led to others sharing their own experiences with children and the conversation then focused on fighting cancer so that the members could recover and still have a share in the lives of their own children. The topic of relationships with children was raised by Pieter, who mentioned that since his diagnosis he had, strangely, become increasingly angry with himself and the whole family situation, over the issue of babysitting. He found it very difficult to say "no" to his children when they wanted him to babysit "their little ones" (his expression). Then, especially during treatment, he frequently fell asleep very early which left his wife to do all the minding thereby putting more pressure on their relationship. He did not feel that this was fair. He said it felt like an extra burden to contend with, over and above what he was already having to endure. This had members relating to Pieter's dilemma. They also loved their children and found it difficult to say "no" when they felt they ought to for their own health's sake. Relenting to the pressure to say "yes" left them feeling that they were being taken "advantage of". Pieter felt that his children did not seem to care what the parent/patient was going through with the cancer treatment, provided the normal routine was kept in place.

Pieter feared that if he said "no" to babysitting that his wife would become angry with him or say that she would look after the children even if Pieter was not feeling up to it thus making him feel more useless and distressed because his "no" had now been overruled which further eroded his authority in his own home. Then there was the dread that one "no" in these circumstances would reduce the amount of times he would then see his children or grandchildren in the future. Merely thinking about the whole situation caused him much stress and irritability. He mentioned that he was to blame for the whole mess. The group discussion then focused on the topic of blame for having the disease: oneself, others, a previous lifestyle, the present worries and even God. The facilitator then pointed out the futility of seeking out someone or something to blame for one's present condition. There were usually many contributory, interacting factors of a biological, psychological and sociological nature in one person's diagnosis and, as time was important, the group would benefit more from a "here and now" approach which concentrated on accepting one's diagnosis and moving towards recovery as many other patients had done.

Another focus the group mentioned was known, unhealthy habits if one wanted to survive. These included smoking, and overindulging in other activities. Pieter then asked how he was going to cope with his predicament of saying "no" without causing a ripple effect of negative outcomes. The consensus of the group was that he and his wife should have an open and honest discussion with their children about babysitting and what Pieter's dilemma was regarding the after-effects of his treatment. Pieter said he would try and resolve the issue and report back.

In early March, the group again discussed pain in general and Pieter's in particular. He was very grateful to the three group members for the previous week's discussions and the feedback that he had received from the others in the form of encouragement during the week on the telephone had been an uplifting experience and a confidence booster. He was grateful to the researcher for arranging an appointment with his oncologist so promptly (while the meeting was in progress) concerning his chest pains. This doctor sent him to a pathologist who explored the problem area, discovered the

cause of the discomfort and treated it immediately. This brought much relief to the whole group (as evidenced by the homework sheets) and served to highlight the crucial honesty that must exist in the patient-doctor communication. In this way, Pieter was an example to the others for the future reporting of any pains suffered before, during and after treatment.

Pieter was always very responsive with his homework concerning that week's meeting and especially so when the group spoke at length about forgiveness of emotional upheaval. This topic centred on the harm that people do to others causing emotional turmoil which could last a long time. The group members shared their experiences of times in their lives when their grief or anger overpowered their Christian sense of forgiving and forgetting (thereby holding no grudges). It was felt by some that some things were unforgiveable. The facilitator mentioned a similar theme in the Thursday (ladies) group and suggested that the men could learn from that discussion. In the process of clearing one's own guilt and conscience (which would effectively reduce psychosocial stress and enhance immune function) from past incidences in each respective life, one then asks the Son of God for forgiveness. One must then forgive "one's neighbour" any transgression. The men's group realised that the ladies made a good point which resulted in a fresh perspective to be considered. The conversation remained on the forgetting of previous harm done by another and how difficult it was to give someone a clean slate, as if nothing had ever happened. Pieter also mentioned how hard he found it was, most times, to forgive oneself even after asking for divine forgiveness. The others felt that, that was a test of one's faith.

The next topic related to restoring one's immune system and how the person's conscience, which played an enormous role in the perception of psychosocial distress, needed attention as the guiding influence in each person's daily life. The group felt that honesty with oneself and with God would have to be entrenched before one could be open and honest with others. This would require training, mentioned another member, and a great deal of time, said another. It was agreed that cancer called for changes in a person's life and that there was no time like the present for making decisions and

implementing them. One might never get such an opportunity again to make these changes in one's life.

At the end of March, Pieter reported feeling very tired after his radiation therapy. He shared his distress with the group that one of his sons-cum-family were going to immigrate to Australia. He asked the researcher if he could organise an appointment with the doctor as he felt he needed medication to control his emotions concerning this news. The appointment was made for after the meeting. In the members' homework it was noted that a great depth of understanding and support had gone out to him. This was maintained in the weeks that followed by getting him to talk openly about the issue while the others listened rather than advised, as no-one had been in a similar predicament. At the next meeting he shared his problem again but in a happier frame of mind, saying that at least he had a new destination for his holidays. This mood prevailed while welcoming a new member into the group. Pieter was able to grow used to feeling that his problem was under control, while still being able to express his emotions in an open manner. He shared this with the new patient and mentioned how much support he had received at the meetings and during the week that followed. This was a major source of encouragement to all present; to see the fruits of their unconditional support.

In April, before the Gauteng school holidays, Pieter joined in the discussion on being in touch with one's real worries. He had found that having cancer confused him about his priorities. At first he could not understand why he spent so much time worrying about trivial issues, when he should have concentrated a little more on his health, diet and relationships rather than getting very angry about a kitchen tap leaking and forgetting who he should contact to fix it. Should he call any plumber or the family friend whose name he could not recall? He was afraid that if he did not get it fixed quickly, his family would think him "nuts" for not remembering his own friend's name. He mentioned that the group had been a great support helping him prioritise his activities while he was having his treatment.

After Three Months Participation

In early May, Pieter told the group that he could no longer come in to Pretoria in the afternoons as his wife needed the family car for her work. The group tried to come up with an alternative plan but he said that it would be better that way as, recently, he had been experiencing more intense pain and the medication for this made him very drowsy and he feared falling asleep at the wheel. He reported that even thinking about driving a motorcar was distressing. The group responded by making a commitment to stay in touch by telephone and Pieter agreed that that would be best considering all he had learnt and achieved in the previous three months. He told the group that since he had been coming every Tuesday, he had found that apart from having to cope with his cancer and concomitant pains and the after effects ("shockwaves" he called them) of his treatment, he took greater pleasure in doing the simple things of life. He spent more and more time with his children: "I enjoy being a child again". He and his wife had discovered a new-found relationship based on friendship, mutual respect and a long-standing love. They had touched more often than had been the case previously, and had begun exploring new conversation topics together, entirely based on openness and honesty. He had "re-discovered his soul-mate" he said. The group listened attentively without interruption. Most present, it was recorded in the homework ("stunned" was one response), were amazed that this was the same Pieter who had hardly opened his mouth three months before at the first meeting. He went on to thank the group members who had helped him re-gain his battered confidence during the storms of the previous months. He shared how his faith in the Lord Jesus Christ had returned. He reported that he spent most of his days in prayer saying "thank you Lord" for all the blessings that he had been given. He was grateful for each new day and its contents. He further felt that, that was the relationship that was having such a positive effect on all the others; with his wife, entire family, some friends and even his doctors. He told the group that he worried less about his future as it was not in his hands, which effectively freed him to do the things he enjoyed doing each day. This, he felt, returned to him a sense of having a more ordered life which had become less stressful. He had more daily choices and was not bound by routine. The group left with a feeling that at least they

could continue their conversations with Pieter by telephone; they had not lost their friend.

From May to July the male group members remained in contact with Pieter and he with them on, roughly, a fortnightly basis. His cancer, in this time, began to spread resulting in more physical pain and psychological depression at his body's failure to respond adequately to treatment and the new restrictions this placed on his lifestyle.

In June, the oncologists decided that more of the right lung had to be removed in an effort to control the spread. After this surgery, Pieter experienced further problems with his breathing which further restricted his movements. He reported that the latest ordeal had brought him closer to his Creator, to whom he prayed even more each day, still thanking Him for each new day's blessings.

This is one case where a lung cancer patient travelled some distance to attend a support group. In itself, this could exacerbate psychosocial distress which would further weaken an already compromised immune system. This case study also serves to highlight the importance of a cancer patient's family needing counselling for the holistic treatment of the patient. They should be seen as part of the treatment team so as not to have unreal expectations about the cancer's condition. The family would also serve as a support in creating the environment where much of what the patient had learnt at the support group, could have been put into practice to enhance immune functioning. Pieter attended nine sessions in three months.

Overview: A Comparison of the Five Case Studies

Five strangers brought their five different personalities with their unique backgrounds to the support group meetings in early 1998 at the Muelmed Hospital cancer clinic in Pretoria. The group for men on a Tuesday afternoon discussed similar themes to those in the Thursday group for women. Each of the five patients in the case studies had a different cancer diagnosis with unique medical treatment schedules and prognosis.

From a psychosocial perspective all five were South African citizens over the age of 45 who had lived through the apartheid system of government in five unique ways given their advantages or disadvantages. All five had been in the country during the transition to the present government and all saw their medical expenses as the least of their worries during the six months of participation in the support groups. All five were employed at the time of their diagnosis except Pieter whose previous employers paid him a pension when he became too ill to work. Four of the five are married and all five have at least two adult children.

Their differences arose, however, in their individual ability to make positive or negative use of the sessions they attended. The following commentary is based on the accumulated data from the three scales administered every three months, the researcher's journal, homework sheets and other communications during the six months.

A feature of Richard's personality was his "blocking out" practice. When having to face any form of distress, he reported that he had trained himself to block it from consciousness. He maintained that it worked to cope with any initial trauma. He knows, through support group participation, that any form of blocking or denial can, and frequently does, impact severely on the immune system. He smiled a great deal when urged by the group to try his apparent openness on the trauma of daily living and talk the problem out with someone special. He said that it would take "training" but that in his daily prayer schedule he had become accustomed to discussing most things with

God, which he felt gave him a feeling that they were under control.

He gave the impression of being well-adjusted and capable of adapting to any change to his lifestyle relating to his cancer. In this regard, he reported a supportive home environment. He hardly ever complained about his state-of-health, preferring to shift the attention to others' problems. However, he reported times when he worried about his erratic sleeping habits, excessive sweating and finding blood in his stool. A group member helped him on this by directing him to the oncologist on duty who immediately sent him for a scan. The incident further enhanced the confidence of the other patients in much more open communication with their specialists. Richard had initiated the establishment of a "dedicated" line with the doctors. Through this experience the other members gradually moved away from the fear and confusion of asking doctors questions about their condition. He led by example and his personality, at best, tended to inspire those nearby to lift their own spirits and fight the disease.

Richard had become much more aware of the stressors that existed in his life and that reducing these with the help of the supports that are in place, could serve to gradually build a healthier quality of life. His input at the group sessions served not only to show others what can be achieved by making important changes in one's lifestyle to help combat the cancer, but also has served to entrench the changes he has already made. He grew in many respects since the group meetings began. At first, dominant and always interrupting others with advice to cope with their problems his way, then eventually relaxing as his own health improved and then, ultimately, his true nature came to the fore bringing a caring listener and leader through his actions. Then others turned to him for direction and his calming influence was a real asset especially as new patients joined the group.

Linda, on the other hand, began attending the sessions from early February 1998 in a quiet and watchful way. She had suffered much in her life and a great deal in the previous three years. Her cancer required a check-up every three months as it had been in remission since March 1998 (she was the only one of the five whose cancer was

first detected two years previously). She joined the group because she had suffered a relapse in early 1998 and was at the clinic for radiation therapy. Since joining the support group she had only missed two meetings; once through 'flu and the other through work commitments. From being withdrawn at first, then later on, reading her son's Mother's Day letter, and absorbing the group's emotional response, to the point of realising that she had a valuable contribution to make to the well-being of the group by just being herself, she improved the quality of life of all those around her.

She was accustomed to "bouncing back" (translated from "terug te kom") from adversity. Simple pleasures at home, at work and at the support group made her content and even joyful on occasions. Her responsibilities and capabilities at her workplace gave her a great sense of satisfaction. Her personality, when it emerged through past accumulated baggage, went a long way towards helping her cope with the adversities that she constantly had to face head-on. She admitted that the support she had received from the group, in and out of the meetings, had become like a buffer against what life had sent her way. Furthermore, she felt that coping alone was not something one should get used to, especially if cancer was one of the factors. She had learned to be more in touch with one's emotions and how to release the pressure of burdensome distress, through talking openly and honestly among those she trusts. She had acquired, as well, the confidence to speak openly to her doctors and report any pain whenever she became aware of it, although, she reported that she would not like to be regarded as a complaining person by nature. Her survival attitude towards life and her motherly instincts have previously stood her in good stead.

The cancer diagnosis, Maurice said, was the opportunity he needed to realise that his explosive anger was detrimental not only to his own health but also to the daily lives of those he loves and people he knows. He learnt through interaction with other cancer patients a way to control this flaw of an otherwise friendly personality. He enjoyed the company of people and they appeared to enjoy him. He laughed easily and had the ability to lighten up a serious conversation with his anecdotes. He also learnt how stress could effect the human immune system and what steps could be taken to

change those aspects of his life which may have lead to his distress.

The support group members continued to benefit from his optimistic attitude towards life even when discussing his "incurable" cancer. When the group heard that it was vastly reduced and under control, verging on remission, it had the effect of instilling an enormous "dose" of hope and optimism for all present. Although concentrating on one day at a time, he admitted to a previous reactive coping style where he frequently caught himself acting on impulse. Lately, eight months after diagnosis, his disease demanded that he make drastic changes to his overall lifestyle which required cementing these changes in place for any chance of recovery to take place. His recently acquired awareness of the advantages of a healthy immune system and how this may be achieved through practice in daily living, ensured an acquired, proactive coping style reinforced by a growing network of supports, including family, friends and fellow cancer patients in the support group.

Maurice's oncologist recently told him that he was one of the three percent of patients with cancer of the pancreas that went into remission after seven months of treatment.

The emotional support he received when exploring solutions to the problem of his rages, he gave back at every meeting in his feedback as an update was supplied about areas where he had been training himself to relax in confrontational situations. Other members drew strength from Maurice implementing their suggestions with success, so that, in turn, they felt encouraged to air their own dilemmas and listen to his often, encouraging remarks about possible solutions. Furthermore, his zest for knowledge about cancer in general and his attitude of refusing to be discouraged in searching for the answers he needed, had an infectious effect on the others to the point where they were empowered to do the same.

In his own way he, too, opened other members', previously blocked, lines of communication with medical staff. As the group progressed, he witnessed the benefits

that his contributions had made to others, and experienced the benefits of his willingness not only to be open to fresh ideas from others, but also to implement those ideas which emanated from the support team.

Janet responded to her diagnosis by accepting the news as if she had been expecting it. She refused to succumb to the temptation to fight another battle alone and looked for empathic support. Her life situation made her feel depressed and lonely, but she coped with those emotions by burying herself in her business. The environment which she had created led eventually to her starting her own company some distance from her source of misery. This allowed her resolute personality to shut out her marital relationship's failure. By her own admission, she became a "work-aholic" (her words) to manage her sanity. Initially, she gave the impression of being well-adjusted, care-free and totally in charge. When she joined the support group, she realised that the members only supported honesty. She battled with such frankness at first, but soon became the champion of sincerity and openness.

Other members realised that they were not alone in the struggle against their disease. She suggested that the members take Jesus as their Saviour and trust His intervention. Once she had renewed and re-established her own relationship with Christ, the new strength and peace she found was shared with all in her company. She reported her latest medical test results as being a God-send: the cancer was under control. No more treatment for the time being and she was to return for a check-up in three months. Her quiet, assertive nature and the fact that she used her own mistakes in the past as object-lessons, served to help the other members in their daily struggles.

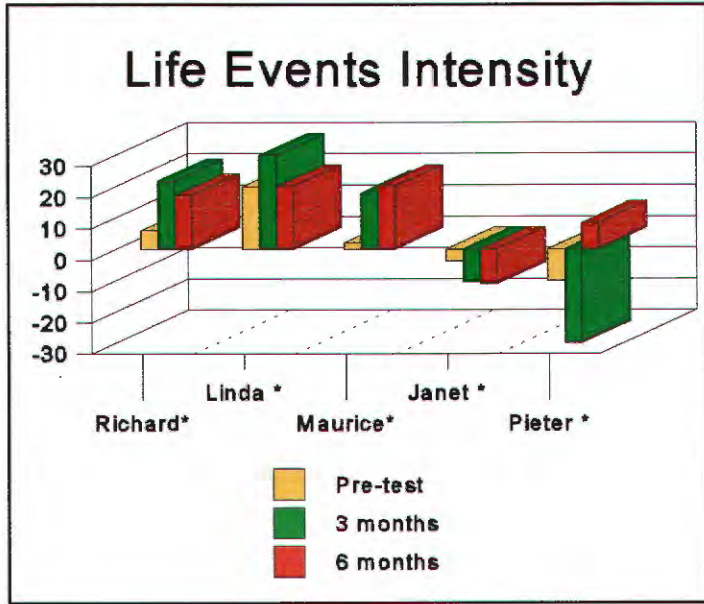
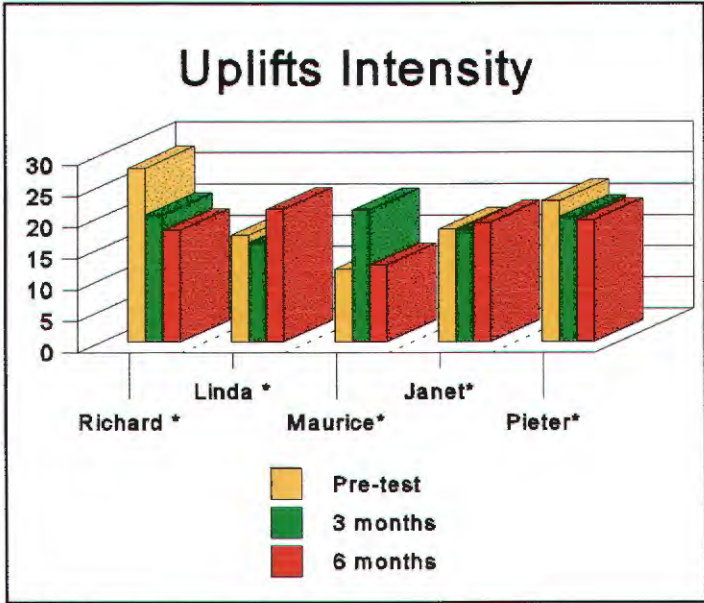
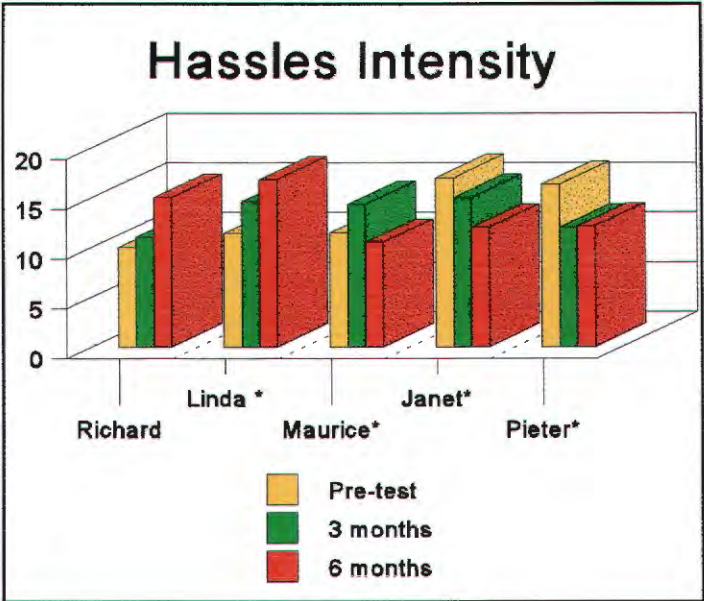
Her first report back started with the words: "I am not alone". Her refusal to deny her predicament and the misery of her marital relationship, arrived at the first meeting like a breath of fresh air. The group had been running for a month when she joined and it became the turning point in her life as well as the other cancer patients. She needed love and support and she received it in abundance. The other members at that time needed to practice being honest with themselves so that they could begin making the

drastic changes necessary in the lives of a cancer patient who really wanted to recover. Janet began the process of relating what real honesty actually entailed. The group interaction received the spark it needed in re-building each one's health through awareness of and actively reducing areas of psychosocial distress.

A little like Linda and Maurice in some respects in their attitudes towards their cancers one characteristic of Pieter's personality was an optimistic outlook on life. When he felt more comfortable with new faces, he removed the defences to show his friendly and affectionate self. He admitted to a certain withdrawal when confronted by a sense of loss of control over a situation. He learnt to adapt that to the demands of cancer. He initially avoided the subject as being, he said: "too serious, my friends around me would not enjoy such a miserable discussion". In time, he gave vent to his emotions and made changes in his lifestyle. He became aware of which ingredients contributed to a more healthy quality of life and gradually adapted his family to fit in with his plans for recovery. His honesty with himself opened up lines of communication in his life that had previously been blocked through fear, anger and frustration. His manner of coping with his disease was strengthened when he shared his traumas with his fellow-patients, and realised that coping with the dilemmas of cancer alone was not an option for survival. His self-esteem grew as he realised the other members enjoyed his company without his having to prove anything. This facet of his personality began to effect his family life in a positive manner which eventually led to his coping with his son's immigration in a happier frame of mind.

He made an instant friend of Maurice who at first seemed the complete opposite in personality, but later when he helped to draw out Pieter's characteristics they were apparent similarities (e.g., a fighting spirit). His family support system appeared to crumble when a son decided to immigrate. Pieter received positive support from his group members and later felt emotionally capable of leading his family to recover from the shock. In telephone conversations after he left the group Pieter seemed happily confident even after his most recent lung operation and reminded the researcher that: "It's all in the Lord's hands, why do I need to worry?". This attitude served to enrich his quality of life.

DIAGRAM 6



* Multiplied by 10 for display purposes

CHAPTER 7

DISCUSSION: A CRITICAL REVIEW

After six months of weekly group meetings, it became apparent from the various sources of feedback, including the three scales, weekly homework sheets and the researchers own journal, that there were positive and negative outcomes.

Strengths and Weaknesses of the Research Method

The Hassles and Uplifts scales and the Life events scale often failed to convey what the patient discussed at the group meetings. In the literature it was evident that the two sets of scales would complement each other if administered simultaneously. The implication was that in looking for areas of distress and support, if the Hassles and Uplifts scales did not accurately present the scenario (even though the final item was open to add what he or she felt was missing and to comment on its effect) then the Life events scale would identify it. Furthermore, many of the items in both sets of scales correspond and the Life events scale, ideally, would expand on certain items in the other two scales.

In the conditions (at the cancer clinic) at the first interview with the patient, when he or she realised that completing the questions would take over an hour(that is, after the brief interview) the researcher permitted the patient to take them home to complete there. After three and six months of participation it became a matter of course for the participants to take them home for completion to be returned the following week. In discussion they reported that it was exhausting to maintain concentration to complete all three scales at once. They admitted doing some in a hurry for this reason.

The researcher, in an effort to ease any stress, felt that the data from group discussions were more important. On reflection this was an error. To do justice to the scales there should have been one session set aside where they could have been

completed within the 90 minutes and any queries about an item answered at that time by the researcher. The alternatives would be to locate a less time consuming set of questionnaires or administer only the Hassles and Uplifts scales (which appear to be effective on their own) in an unstressful environment such as the regular venue. Also, completing the scales away from the group reduces the focus of discussion. It is a fact that chemotherapy and head and neck radiation can have a detrimental effect on one's short term memory during the course of treatment and for a while afterwards. In one instance, the group member asked if he could prepare a topic of personal concern for the following week's meeting and even though this was encouraged, he admitted that he had forgotten immediately after the session. He reported feeling upset at his failure to remember despite the others telling him that it had been important to him. As the group members were all in various stages of various forms of treatment, the actual sources of stress may have been hazy, leaving their responses less thorough.

The researcher understood their forgetfulness as not being deliberately evasive but did discuss the items in contention and made notes accordingly. In many cases the homework sheets were incomplete and off the topics that were discussed. Nevertheless, they provided some insight into what the particular patient had gained from the particular session. Some valuable suggestions were: "more on immune system, please", "ask Dr Georges to attend to answer questions" and "I have heard that chemotherapy can be poisonous-is it true?".

This leads to another flaw in the research method. After each session the researcher reported in his on-going journal about the themes and issues that had been discussed on a particular day. This was an inefficient and insufficient method of capturing the richness of each patient's exploration of a dilemma that was important to him or her. In order to improve the analysis and description of the contents of each session and capture the processes of motion in interactions (progress was often positive and negative in some sessions) at least a tape recorder should have been used at each meeting to assist in accuracy of recall. Notes would still have a place in the accumulation of documentation to record non-verbal communications. Ideally, a video

camera would have enhanced accuracy.

This lack of backup to support the researcher's own notes highlights another flaw in the sessions. The researcher was the group facilitator and the assessor of information gleaned from the meetings. This major bias which concerned the how, what, why, where and when of information gathering could have been circumvented had an independent assessor been present. Ideally, the ex-patient as group co-ordinator and a professional group worker should facilitate the group together so that the experiential richness of the members could be more adequately used in the therapeutic processes as guided by the professional. The co-facilitator would have added to the information in the documentation and, ideally, dovetailed (i.e., filled the gaps) with the information the researcher had observed and recorded. This arrangement may have further facilitated the group members, in the confidential setting, to move away from conversational politeness (most evident when a new member arrived) and explore the depths of their cancer and their responses to the treatment. More details of how degrading (e.g., cleaning up after prolonged or intense irradiation has effected the sphincter muscle or how chemotherapy induces bile vomiting) and demeaning their disease had become may have emerged. Moreover, the patient's own distress upon seeing loved-ones' reactions to the unpleasant side-effects of cancer could have been explored. If the co-facilitator had been a social worker, for example, the family system interaction could have been managed more effectively and less stressfully with appropriate professional intervention.

A further weakness was the use of small samples of convenience. The situation of recruitment of volunteer out-patients was one where the researcher relied on the medical staff (i.e., radiographers, doctors and ward sisters) to select appropriate patients. The researcher designed the letter of introduction (Appendix E) but was not in a position to constantly approach newly diagnosed patients in the waiting rooms. Furthermore, the medical staff were frequently too busy to always remember that the support group was being offered (despite an A4-sized notice in one waiting room) and many patients were not informed. However, when the groups began in the first week

of February the members asked the researcher to restrict the group size to no more than six in a session. They felt that more than six would inhibit the opportunities to discuss personal issues.

Another weakness concerned the absence of any control (i.e., non-treatment) group for comparison purposes. This omission meant that the effectiveness of the intervention in helping each patient to manage areas of distress through open discussion with peers could not be measured against a group which was not given such an opportunity. In discussion with medical personnel this seemed always to be the case with out-patient research. It was also revealed that the same applied to in-patient studies as patients were often discharged before the study ended "no matter the agreement" said one nursing sister. The medical staff did not like the thought of some patients being asked to volunteer for the research and then being told they were not to attend the group meetings. Besides many confounding variables in a patient's life, it was further suggested by the clinic staff and agreed to by the researcher, that cancer was an illness where a patient spent a great deal of time on a stressful knife edge in many aspects of biopsychosocial uncertainty that to deny that patient an opportunity to participate in a research project that may relieve some distress was unethical. In this regard, another weakness of the research method was the low generalisability of the findings. In order to generalise outcome material to other support groups the research requirements would have entailed an experimental design where, amongst other aspects, patients would be randomly selected to participate and randomly assigned to a control and treatment group. Even cancer in-patients make the possibility of this design unfeasible in accounting for all contaminating variables.

On the other hand, the low generalisability serves to highlight one of the strengths of the study. This refers to the transferability of themes, questions and concepts to similar studies. These studies would then benefit from the pilot research without considering repeatability as a criterion. The topics raised in the pilot meetings would serve as ideas for future research. This has led to the patients and facilitator setting in motion the development of a workshop manual for cancer patients and survivors to

start their own self-help support groups in their home towns.

A further methodological strength of this study and one of the core issues over large samples, was that there was more individual attention and therefore greater opportunity for personal growth for each patient in a small group. Each patient found that it was comfortable in the confidential atmosphere of the regular room where it allowed one to feel safe and at ease once everyone present had introduced themselves with their particular background and cancer. Some members took one or two meetings to relax and feel part of proceedings as they were drawn into discussion. It was felt that perhaps this process of acclimatisation would have taken longer if there had been more patients at each meeting.

Strengths and Weaknesses of the Intervention

One of the weaknesses of this intervention became apparent in the first week of February 1998 when the meetings began. The researcher had planned on mixed gender groups but when the three women who had volunteered for the first Tuesday meeting did not arrive, the three men present (excluding the facilitator) proceeded in the discussions as if that was what they wanted. The facilitator, later in the meeting, told them what had happened and they unanimously decided that the group remain only for men. The same thing occurred on the first Thursday in February. The men who had volunteered did not arrive and the four women present, on hearing what had occurred at the Tuesday meeting, decided that it suited them as well. The men had felt it better because in venting the side-effects of some patients response to treatment there were possibly embarrassing things such as, never having experienced one before, an intense course of radiation led to a grand mal seizure in the company of family and friends and being told about everything later in hospital. It was felt that with ladies present such conversations in "getting things off one's chest" (a member's expression) would be inhibited. This was agreed to be detrimental to future discussion topics. The women felt the same way. These events led to two unhappy occurrences in February when two men volunteered to join the Tuesday group and served to highlight a weakness in the

intervention. Both men arrived with their wives intending to participate together. The other group members voiced their disapproval on discovering that the wives did not have cancer. They pointed out that the husband could recount what he had learned from the proceedings later at home. The wives were asked to leave. The husbands only attended the one session. The outcome was two brief letters from the men addressed to the researcher explaining that their wives' attendance was important to them and that they would probably receive better support at their homes. These incidents caused the members present much distress and guilt about their roles. This was discussed to clear the atmosphere of regret. It had provided a useful reminder that the patient's family was crucial to recovery. The researcher replied to the two men that he had found out that the Hospice Association provided support groups for families of cancer patients on a regular basis. An ideal scenario may be that the patient attends a support group alone and then accompanies the spouse to the family support group being held elsewhere to more openly discuss important issues.

Another weakness of this intervention was that not all patients resided within easy reach of the support group and many found the extra travelling distressing particularly if they had recently undergone chemotherapy or radiation treatment. Perhaps a more readily available venue would have enhanced group participation as there would be less anxiety about possible traffic congestion on the way home. In this regard, another weakness arose when patients who lived at a considerable distance from the city would find temporary accommodation near the hospital for the duration of the medical treatment and join the support group for that period only. On a few occasions this arrangement served to interrupt the continuity of the sessions. Newly formed friendships had to be ended when the treatment was over and affected already fragile emotions. These patients were often farmers who needed to leave in a hurry to tend to other priorities but still managed to attend three or four meetings and make contributions to the other members' knowledge about cancer and its impact on a person's psychosocial environment.

However, from the documentation collected from and about those who attended

regularly, there were strengths to the intervention. Firstly, previously blocked lines of communication were opened and the group members tended to gain more confidence in frank discussions about their own psychosocial concerns. They reported feeling better equipped to manage important relationships in their lives. Secondly, that through the group involvement over a period of time, each cancer patient experienced a richer quality of life while living with cancer, even in dying. A shared awareness of ways in which one could still enjoy moments of every day without being afraid of the future was frequently mentioned in feedback. Thirdly, there was a greater awareness of how an immune system functions at optimum and how the idea of reducing one's psychosocial distress (having recognised it as such) helps to promote this. It became evident in group discussion that immuno-efficiency centred on a lasting awareness of what the patient felt was beneficial to his or her system at any one moment. The accumulated, recent research on the topic served to enhance the members' knowledge about their own condition. Finally, it was noticeable that during the group process the patients found a social safety net of family and friends which tended to encourage them to become more involved in community activities such as (these were undertaken) entering a charity walk to raise money for street children and participating in a Saturday morning street collection.

CHAPTER 8

CONCLUSIONS AND FUTURE RESEARCH DIRECTIONS

The case studies convey some of the realities of the lives of five cancer patients. The weekly support groups in which they participated served to highlight some common ground in the medical, social and psychological spheres of cancer treatment. Cancer is an extremely individualistic disease, given each person's unique DNA characteristics in interaction with their own psychosocial environment. Cancer, from the first diagnosis onward, places one in a very lonely position and with that sense of being isolated comes the pervasive fear and absolute confusion within a great many unknown ("What If", from a cancer patient) factors. Physical pain interacting within a person's biopsychosocial lifestyle, varies from person to person.

The newly diagnosed cancer patient needs an opportunity to talk openly in a confidential environment with people who can empathise (rather than sympathise) and share such matters as:

1. How one's body is responding to medical treatment with its concomitant symptoms
2. The psychosocial distress involved in their (for example) loneliness, fear and loss of control over their bodies and much of their lives
3. Feeling more confident to request more knowledge about one's cancer
4. Learning to slowly repair and re-build relationships
5. Making changes in one's lifestyle to enhance immune function
6. Acquiring necessary emotional support via verbal and non-verbal communication

Cancer patient support groups potentially provide for such an opportunity. Should they meet on a regular basis (at least twice a month) the patients would soon develop a feeling that they are not alone in coping with their cancer. While learning to manage their lives from an immune-conscious perspective, a growing confidence/faith among fellow patients that the disease can be cured with a mind-body-soul approach to

treatment, serves to open previously blocked or damaged lines of communication. This facilitates not only their asking for much needed information (not only about the cancer, *per se*) but also relating openly about their psychosocial distress.

In South Africa, people with cancer are treated medically in an urban environment. At present, the support groups at Muelmed Hospital function in the same environment which frequently entails patients participating in the groups on different days to their medical treatment. The extra travelling increases distress and therefore undermines any healthy progress made in the support group meeting.

Future research should, therefore, be aimed at starting cancer self-help groups near to where the patient-population reside. Future hypotheses that would also require investigation would be:

1. Patients who are initially diagnosed with cancer manifest a higher level of unresolved psychosocial distress as measured on the Hassles and Life Events Scales.
2. Unresolved psychosocial distress influences response to chemotherapy and radiation treatment.
3. Individuals who engage in a support group, will reduce levels of psychological morbidity brought about by unresolved psychosocial distress and bring about a more positive response to treatment.

Recent research (Armario, Marti, Molina, De Pablo & Valdes, 1996) indicates that stress markers in human blood samples may be useful mechanisms, using an experimental research design, in determining the effectiveness of any psychosocial intervention, such as a support group, running parallel with the cancer patient's medical treatment. The stress markers are plasma glucose, cortisol and prolactin.

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APPENDIX A

Study of Support Groups in Cancer Treatment

Consent Form

I hereby give permission for the administration of a questionnaire to myself as explained to me by

I understand that the results of this study will be published, but that my personal particulars will be treated with strict confidentiality at all times.

I understand that participation in this project is entirely voluntary and that I can withdraw at any time.

Toestemmingsvorm

Ek,, gee hiermee my toestemming om 'n vraelys te beantwoord soos aan my verduidelik is deur

Ek neem kennis en verstaan dat die resultate van hierdie studie gepubliseer sal word, maar dat informasie oor my persoonlik te alle tye as streng vertroulik hanteer sal word.

Ek verstaan verder dat deelname aan die projek heeltemal vrywillig is, en ek kan op enige stadium van hierdie projek onttrek.

SIGNED/GETEKEN:.....

DATE/DATUM: STUDY/STUDIE NO.:.....

APPENDIX B

THE HASSLES SCALE

(The Afrikaans version is at hand)

Directions: Hassles are irritants that can range from minor annoyances to fairly major pressures, problems, or difficulties. They can occur a few or many times.

Listed in the centre of the following pages are a number of ways in which a person can feel hassled. First, circle the hassles that have happened to you in the past month. Then look at the numbers on the right of the items you circled. Indicate by circling a 1, 2, or 3 how SEVERE each of the circled hassles has been for you in the past month, and with a 0 if it appeared and had no effect. If a hassle did not occur in the last month do NOT circle it.

HASSLES	How serious was it?			
	0.	No effect		
	1.	Not very serious		
	2.	Reasonably serious		
	3.	Very serious		
1) Misplacing or losing things	0	1	2	3
2) Troublesome neighbours	0	1	2	3
3) Social obligations	0	1	2	3
4) Inconsiderate smokers	0	1	2	3
5) Troubling thoughts about your future	0	1	2	3
6) Thoughts about death	0	1	2	3
7) Health of a family member	0	1	2	3
8) Not enough money for clothing	0	1	2	3
9) Not enough money for housing	0	1	2	3
10) Concerns about owing money	0	1	2	3
11) Concerns about getting credit	0	1	2	3
12) Concerns about money for emergencies	0	1	2	3
13) Someone owes you money	0	1	2	3
14) Financial responsibility for someone who doesn't live with you	0	1	2	3

HASSLES		How serious was it?			
		0.	No effect		
		1.	Not very serious		
		2.	Reasonably serious		
		3.	Very serious		
15)	Cutting down on electricity, water, etc.	0	1	2	3
16)	Smoking too much	0	1	2	3
17)	Use of alcohol	0	1	2	3
18)	Personal use of drugs	0	1	2	3
19)	Too many responsibilities	0	1	2	3
20)	Decisions about having children	0	1	2	3
21)	Non-family members living in your house	0	1	2	3
22)	Care for pet	0	1	2	3
23)	Planning meals	0	1	2	3
24)	Concerned about the meaning of life	0	1	2	3
25)	Trouble relaxing	0	1	2	3
26)	Trouble making decisions	0	1	2	3
27)	Problems getting along with fellow workers	0	1	2	3
28)	Customers or clients give you a hard time	0	1	2	3
29)	Home maintenance (inside)	0	1	2	3
30)	Concerns about job security	0	1	2	3
31)	Concerns about retirement	0	1	2	3
32)	Laid-off or out of work	0	1	2	3
33)	Don't like current work duties	0	1	2	3
34)	Don't like fellow workers	0	1	2	3
35)	Not enough money for basic necessities	0	1	2	3
36)	Not enough money for food	0	1	2	3
37)	Too many interruptions	0	1	2	3
38)	Unexpected company	0	1	2	3
39)	Too much time on hands	0	1	2	3
40)	Having to wait	0	1	2	3
41)	Concerns about accidents	0	1	2	3
42)	Being lonely	0	1	2	3
43)	Not enough money for health care	0	1	2	3
44)	Fear of confrontation	0	1	2	3

HASSLES		How serious was it?			
		0.	No effect		
		1.	Not very serious		
		2.	Reasonably serious		
		3.	Very serious		
45)	Financial security	0	1	2	3
46)	Silly practical mistakes	0	1	2	3
47)	Inability to express yourself	0	1	2	3
48)	Physical illness	0	1	2	3
49)	Side effects of medication	0	1	2	3
50)	Concerns about medical treatment	0	1	2	3
51)	Physical appearance	0	1	2	3
52)	Fear of rejection	0	1	2	3
53)	Difficulties with getting pregnant	0	1	2	3
54)	Sexual problems that result from physical problems	0	1	2	3
55)	Sexual problems other than those resulting from physical problems	0	1	2	3
56)	Concerns about health in general	0	1	2	3
57)	Not seeing enough people	0	1	2	3
58)	Friends or relatives too far away	0	1	2	3
59)	Preparing meals	0	1	2	3
60)	Wasting time	0	1	2	3
61)	Auto maintenance	0	1	2	3
62)	Filling out forms	0	1	2	3
63)	Neighbourhood deterioration	0	1	2	3
64)	Financing children's education	0	1	2	3
65)	Problems with employees	0	1	2	3
66)	Problems on job due to being woman or man	0	1	2	3
67)	Declining physical abilities	0	1	2	3
68)	Being exploited	0	1	2	3
69)	Concerns about bodily functions	0	1	2	3
70)	Rising prices of common goods	0	1	2	3
71)	Not getting enough rest	0	1	2	3
72)	Not getting enough sleep	0	1	2	3
73)	Problems with ageing parents	0	1	2	3

HASSLES	How serious was it?			
	0.	No effect		
	1.	Not very serious		
	2.	Reasonably serious		
	3.	Very serious		
74) Problems with your children	0	1	2	3
75) Problems with persons younger than yourself	0	1	2	3
76) Problems with lover	0	1	2	3
77) Difficulties seeing or hearing	0	1	2	3
78) Overloaded with family responsibilities	0	1	2	3
79) Too many things to do	0	1	2	3
80) Unchallenging work	0	1	2	3
81) Concerns about meeting high standards	0	1	2	3
82) Financial dealings with friends or acquaintances	0	1	2	3
83) Job dissatisfaction	0	1	2	3
84) Worries about decisions to change jobs	0	1	2	3
85) Trouble with reading, writing, or spelling abilities	0	1	2	3
86) Too many meetings	0	1	2	3
87) Problems with divorce or separation	0	1	2	3
88) Trouble with arithmetic skills	0	1	2	3
89) Gossip	0	1	2	3
90) Legal problems	0	1	2	3
91) Concerns about weight	0	1	2	3
92) Not enough time to do the things you need to do	0	1	2	3
93) Television	0	1	2	3
94) Not enough personal energy	0	1	2	3
95) Concerns about inner conflicts	0	1	2	3
96) Feel conflicted over what to do	0	1	2	3
97) Regrets over past decisions	0	1	2	3
98) Menstrual (period) problems	0	1	2	3
99) The weather	0	1	2	3
100) Nightmares	0	1	2	3
101) Concerns about getting ahead	0	1	2	3
102) Hassles from boss or supervisor	0	1	2	3

HASSLES	How serious was it?			
	0.	No effect		
	1.	Not very serious		
	2.	Reasonably serious		
	3.	Very serious		
103) Difficulties with friends	0	1	2	3
104) Not enough time for family	0	1	2	3
105) Transportation problems	0	1	2	3
106) Not enough money for transportation	0	1	2	3
107) Not enough money for entertainment and recreation	0	1	2	3
108) Shopping	0	1	2	3
109) Prejudice and discrimination from others	0	1	2	3
110) Property, investments or taxes	0	1	2	3
111) Not enough time for entertainment and recreation	0	1	2	3
112) Yardwork or outside home maintenance	0	1	2	3
113) Concerns about news events	0	1	2	3
114) Noise	0	1	2	3
115) Crime	0	1	2	3
116) Traffic	0	1	2	3
117) Pollution	0	1	2	3
HAVE I MISSED ANY OF YOUR HASSLES? IF SO, WRITE THEM IN BELOW:				
118)	0	1	2	3
ONE MORE THING: HAS THERE BEEN A CHANGE IN YOUR LIFE THAT AFFECTED HOW YOU ANSWERED THIS SCALE? IF SO, TELL ME WHAT IT WAS:				

APPENDIX C

THE UPLIFTS SCALE

(The Afrikaans version is at hand)

Directions: Uplifts are events that make you feel good. They can be sources of peace, satisfaction, or joy. Some occur often, others are relatively rare.

On the following pages, circle the events that have made you feel good in the **past month**. Then look at the numbers on the right of the items you circled. Indicate by circling a 1, 2, or 3 how **OFTEN** each of the **circled** uplifts has been for you in the **past month**. If an item did occur in the last month, but had no effect on you, then circle the 0.

UPLIFTS	How often?			
	0.	No effect		
	1.	Not often		
	2.	Reasonably often		
	3.	Extremely often		
1) Getting enough sleep	0	1	2	3
2) Practising your hobby	0	1	2	3
3) Being lucky	0	1	2	3
4) Saving money	0	1	2	3
5) Nature	0	1	2	3
6) Liking fellow workers	0	1	2	3
7) Not working (on vacation, laid-off, etc.)	0	1	2	3
8) Gossiping	0	1	2	3
9) Successful financial dealings	0	1	2	3
10) Being rested	0	1	2	3
11) Feeling healthy	0	1	2	3
12) Finding something presumed lost	0	1	2	3
13) Recovering from illness	0	1	2	3
14) Staying or getting in good physical shape	0	1	2	3
15) Being with children	0	1	2	3

UPLIFTS	How often?				
	0. No effect				
	1. Not often				
	2. Reasonably often				
	3. Extremely often				
16) "Pulling something off"; getting away with something	0	1	2	3	
17) Visiting, phoning, or writing to someone	0	1	2	3	
18) Relating well with your spouse or lover	0	1	2	3	
19) Completing a task	0	1	2	3	
20) Giving a compliment	0	1	2	3	
21) Meeting family responsibilities	0	1	2	3	
22) Relating well with friends	0	1	2	3	
23) Being efficient	0	1	2	3	
24) Meeting your responsibilities	0	1	2	3	
25) Quitting or cutting down on alcohol	0	1	2	3	
26) Quitting or cutting down on smoking	0	1	2	3	
27) Solving an ongoing practical problem	0	1	2	3	
28) Daydreaming	0	1	2	3	
29) Weight	0	1	2	3	
30) Financially supporting someone who doesn't live with you	0	1	2	3	
31) Sex	0	1	2	3	
32) Friendly neighbours	0	1	2	3	
33) Having enough time to do what you want	0	1	2	3	
34) Divorce or separation	0	1	2	3	
35) Eating out	0	1	2	3	
36) Having enough (personal) energy	0	1	2	3	
37) Resolving inner conflicts	0	1	2	3	
38) Being with older people	0	1	2	3	
39) Finding no prejudice or discrimination when you expect to	0	1	2	3	
40) Cooking	0	1	2	3	
41) Capitalising on an unexpected opportunity	0	1	2	3	
42) Using drugs or alcohol	0	1	2	3	
43) Life being meaningful	0	1	2	3	

UPLIFTS	How often?			
	0.	No effect		
	1.	Not often		
	2.	Reasonably often		
	3.	Extremely often		
44) Being well-prepared	0	1	2	3
45) Eating	0	1	2	3
46) Relaxing	0	1	2	3
47) Having the "right" amount of things to do	0	1	2	3
48) Being visited, phoned, or sent a letter	0	1	2	3
49) The weather	0	1	2	3
50) Thinking about the future	0	1	2	3
51) Spending time with family	0	1	2	3
52) Home (inside) pleasing to you	0	1	2	3
53) Being with younger people	0	1	2	3
54) Buying things for the house	0	1	2	3
55) Reading	0	1	2	3
56) Shopping	0	1	2	3
57) Smoking	0	1	2	3
58) Buying clothes	0	1	2	3
59) Giving a present	0	1	2	3
60) Getting a present	0	1	2	3
61) Becoming pregnant or contributing thereto	0	1	2	3
62) Having enough money for health care	0	1	2	3
63) Travelling or commuting	0	1	2	3
64) Doing yardwork or outside housework	0	1	2	3
65) Having enough money for transportation	0	1	2	3
66) Health of a family member improving	0	1	2	3
67) Resolving conflicts over what to do	0	1	2	3
68) Thinking about health	0	1	2	3
69) Being a "good" listener	0	1	2	3
70) Socialising (parties, being with friends, etc.)	0	1	2	3
71) Making a friend	0	1	2	3

UPLIFTS	How often?				
	0. No effect				
	1. Not often				
	2. Reasonably often				
	3. Extremely often				
72) Sharing something	0	1	2	3	
73) Having someone listen to you	0	1	2	3	
74) Your yard or outside of house is pleasing	0	1	2	3	
75) Looking forward to retirement	0	1	2	3	
76) Having enough money for entertainment and recreation	0	1	2	3	
77) Entertainment (movies, concerts, TV, etc.)	0	1	2	3	
78) Good news on local or world level	0	1	2	3	
79) Getting good advice	0	1	2	3	
80) Recreation (sports, games, hiking, etc.)	0	1	2	3	
81) Paying off debts	0	1	2	3	
82) Using skills well at work	0	1	2	3	
83) Past decisions "panning out"	0	1	2	3	
84) Growing as a person	0	1	2	3	
85) Being complimented	0	1	2	3	
86) Having good ideas at work	0	1	2	3	
87) Improving or gaining new skills	0	1	2	3	
88) Job satisfying despite discrimination due to your sex	0	1	2	3	
89) Free time	0	1	2	3	
90) Expressing yourself well	0	1	2	3	
91) Laughing	0	1	2	3	
92) Vacationing without spouse or children	0	1	2	3	
93) Liking work duties	0	1	2	3	
94) Having good credit	0	1	2	3	
95) Music	0	1	2	3	
96) Getting unexpected money	0	1	2	3	
97) Changing jobs	0	1	2	3	
98) Dreaming	0	1	2	3	
99) Having fun	0	1	2	3	

UPLIFTS	How often?			
	0.	No effect		
	1.	Not often		
	2.	Reasonably often		
	3.	Extremely often		
100) Going some place that's different	0	1	2	3
101) Deciding to have children	0	1	2	3
102) Enjoying non-family members living in your house	0	1	2	3
103) Pets	0	1	2	3
104) Car working/running well	0	1	2	3
105) Neighbourhood improving	0	1	2	3
106) Children's accomplishments	0	1	2	3
107) Things going well with employee(s)	0	1	2	3
108) Pleasant smells	0	1	2	3
109) Getting love	0	1	2	3
110) Successfully avoiding or dealing with bureaucracy or institutions	0	1	2	3
111) Making decisions	0	1	2	3
112) Thinking about the past	0	1	2	3
113) Giving good advice	0	1	2	3
114) Praying	0	1	2	3
115) Meditating	0	1	2	3
116) Fresh air	0	1	2	3
117) Confronting someone or something	0	1	2	3
118) Being accepted	0	1	2	3
119) Giving love	0	1	2	3
120) Boss pleased with your work	0	1	2	3
121) Being alone	0	1	2	3
122) Feeling safe	0	1	2	3
123) Working well with fellow workers	0	1	2	3
124) Knowing your job is secure	0	1	2	3
125) Feeling safe in your neighbourhood	0	1	2	3
126) Doing volunteer work	0	1	2	3
127) Contributing to a charity	0	1	2	3
128) Learning something	0	1	2	3
129) Being "one" with the world	0	1	2	3

UPLIFTS	How often?			
	0.	No effect		
	1.	Not often		
	2.	Reasonably often		
	3.	Extremely often		
130) Fixing/repairing something (besides at your job)	0	1	2	3
131) Making something (besides at your job)	0	1	2	3
132) Exercising	0	1	2	3
133) Meeting a challenge	0	1	2	3
134) Hugging and/or kissing	0	1	2	3
135) Flirting	0	1	2	3
HAVE I MISSED ANY OF YOUR UPLIFTS? IF SO, WRITE THEM IN BELOW:				
136)	0	1	2	3
ONE MORE THING: HAS THERE BEEN A CHANGE IN YOUR LIFE THAT AFFECTED HOW YOU ANSWERED THIS SCALE? IF SO, TELL ME WHAT IT WAS:				

APPENDIX D

THE PERI-LIFE EVENTS

(The Afrikaans version is at hand)

On the following pages, circle the events that sometimes cause changes in the lives of those who experience changes and could cause social adaptiveness. Please mark the numbers at the left of the item which you experienced recently and complete the column during which period you had this experience. Also indicate in the right hand column during what period you had this experience.

Indicate each marked item in what way you think this experience affected your life either positively or negatively when it happened. Indicate what effect it had on you and how severe you experienced this event. A -3 will indicate a very negative effect, 0 will indicate no effect, and a +3 will show a very positive effect.

Question	From ____ to ____	From ____ to ____	Very nega- tive	Mode- rately nega- tive	Slightl y nega- tive	NO EF- FECT	Some what posi- tive	Mode- rately posi- tive	Extre- mely posi- tive
SCHOOL									
1. Started school or a training programme after not going to school for a long time			-3	-2	-1	0	1	2	3
2. Changed schools or training programmes .			-3	-2	-1	0	1	2	3
3. Graduated from school or training programme			-3	-2	-1	0	1	2	3
4. Had problems in school or in training programme			-3	-2	-1	0	1	2	3
5. Failed school, training programme			-3	-2	-1	0	1	2	3

Question	From _____ to _____	From _____ to _____	Very nega- tive	Mode- rately nega- tive	Slightl y nega- tive	NO EF- FECT	Some what posi- tive	Mode- rately posi- tive	Extre- mely posi- tive
6. Did not graduate from school or training programme			-3	-2	-1	0	1	2	3
WORK									
7. Started work for the first time			-3	-2	-1	0	1	2	3
8. Returned to work after not working for a long time			-3	-2	-1	0	1	2	3
9. Changed jobs for a better one			-3	-2	-1	0	1	2	3
10. Changed jobs for a worse one			-3	-2	-1	0	1	2	3
11. Changed jobs for one that was not better and no worse than the last one ..			-3	-2	-1	0	1	2	3
12. Had trouble with a boss			-3	-2	-1	0	1	2	3
13. Demoted at work ..			-3	-2	-1	0	1	2	3
14. Found out that you were <i>not</i> going to be promoted at work ..			-3	-2	-1	0	1	2	3
15. Conditions at work got worse, other than demotion or trouble with the boss			-3	-2	-1	0	1	2	3
16. Promoted			-3	-2	-1	0	1	2	3
17. Had significant success at work ...			-3	-2	-1	0	1	2	3
18. Conditions at work improved, <i>not</i> counting promotion or other personal successes			-3	-2	-1	0	1	2	3
19. Laid off			-3	-2	-1	0	1	2	3

Question	From _____ to _____	From _____ to _____	Very nega- tive	Mode- rately nega- tive	Slightl y nega- tive	NO EF- FECT	Some what posi- tive	Mode- rately posi- tive	Extre- mely posi- tive
20. Fired			-3	-2	-1	0	1	2	3
21. Started a business or profession			-3	-2	-1	0	1	2	3
22. Expanded business or professional practice			-3	-2	-1	0	1	2	3
23. Took on a greatly increased work load			-3	-2	-1	0	1	2	3
24. Suffered a business loss or failure			-3	-2	-1	0	1	2	3
25. Sharply reduced work load			-3	-2	-1	0	1	2	3
26. Retire			-3	-2	-1	0	1	2	3
27. Stopped working, <i>not</i> retirement, for an extended period ..			-3	-2	-1	0	1	2	3
LOVE AND MARRIAGE									
28. Became engaged .			-3	-2	-1	0	1	2	3
29. Engagement was broken			-3	-2	-1	0	1	2	3
30. Married			-3	-2	-1	0	1	2	3
31. Started a love affair			-3	-2	-1	0	1	2	3
32. Relations with spouse changed for the worse, without separation or divorce			-3	-2	-1	0	1	2	3
33. Married couple separated			-3	-2	-1	0	1	2	3
34. Divorce			-3	-2	-1	0	1	2	3
35. Relations with spouse changed for the better			-3	-2	-1	0	1	2	3
36. Married couple got together			-3	-2	-1	0	1	2	3

Question	From _____ to _____	From _____ to _____	Very nega- tive	Mode- rately nega- tive	Slightl y nega- tive	NO EF- FECT	Some what posi- tive	Mode- rately posi- tive	Extre- mely posi- tive
37. Marital infidelity . . .			-3	-2	-1	0	1	2	3
38. Trouble with in-laws			-3	-2	-1	0	1	2	3
39. Spouse died			-3	-2	-1	0	1	2	3
HAVING CHILDREN									
40. Became pregnant .			-3	-2	-1	0	1	2	3
41. Birth of a first child			-3	-2	-1	0	1	2	3
42. Birth of a second or later child			-3	-2	-1	0	1	2	3
43. Abortion			-3	-2	-1	0	1	2	3
44. Miscarriage or stillbirth			-3	-2	-1	0	1	2	3
45. Found out that cannot have children			-3	-2	-1	0	1	2	3
46. Child died			-3	-2	-1	0	1	2	3
47. Adopted a child . . .			-3	-2	-1	0	1	2	3
48. Started menopause			-3	-2	-1	0	1	2	3
FAMILY									
49. New person moved into the household .			-3	-2	-1	0	1	2	3
50. Person moved out of the household			-3	-2	-1	0	1	2	3
51. Someone stayed on in the household after he was expected to leave .			-3	-2	-1	0	1	2	3
52. Serious family argument other than with spouse			-3	-2	-1	0	1	2	3
53. A change in the frequency of family get-togethers			-3	-2	-1	0	1	2	3

Question	From _____ to _____	From _____ to _____	Very nega- tive	Mode- rately nega- tive	Slightl y nega- tive	NO EF- FECT	Some what posi- tive	Mode- rately posi- tive	Extre- mely posi- tive
54. Family member other than spouse or child dies			-3	-2	-1	0	1	2	3
RESIDENCE									
55. Moved to a better residence or neighbourhood ...			-3	-2	-1	0	1	2	3
56. Moved to a worse residence or neighbourhood ...			-3	-2	-1	0	1	2	3
57. Moved to a residence or neighbourhood no better or no worse than the last one ..			-3	-2	-1	0	1	2	3
58. Unable to move after expecting to be able to move			-3	-2	-1	0	1	2	3
59. Built a home or had one built			-3	-2	-1	0	1	2	3
60. Remodelled a home			-3	-2	-1	0	1	2	3
61. Lost a home through fire, flood or other disaster			-3	-2	-1	0	1	2	3
CRIME AND LEGAL MATTERS									
62. Assaulted			-3	-2	-1	0	1	2	3
63. Robbed			-3	-2	-1	0	1	2	3
64. Accident in which there were no injuries			-3	-2	-1	0	1	2	3
65. Involved in a lawsuit			-3	-2	-1	0	1	2	3

Question	From _____ to _____	From _____ to _____	Very nega- tive	Mode- rately nega- tive	Slightl y nega- tive	NO EF- FECT	Some what posi- tive	Mode- rately posi- tive	Extre- mely posi- tive
66. Accused of something for which a person could be sent to jail			-3	-2	-1	0	1	2	3
67. Lost drivers license			-3	-2	-1	0	1	2	3
68. Arrested			-3	-2	-1	0	1	2	3
69. Went to jail			-3	-2	-1	0	1	2	3
70. Got involved in a court case			-3	-2	-1	0	1	2	3
71. Convicted of a crime			-3	-2	-1	0	1	2	3
72. Acquitted from jail .			-3	-2	-1	0	1	2	3
73. Released from jail .			-3	-2	-1	0	1	2	3
74. Didn't get out of jail when expected ...			-3	-2	-1	0	1	2	3

FINANCES

75. Took out a mortgage			-3	-2	-1	0	1	2	3
76. Started buying a car, furniture or other large purchase on the instalment plan			-3	-2	-1	0	1	2	3
77. Foreclosure of a mortgage or loan ..			-3	-2	-1	0	1	2	3
78. Repossession of a car, furniture or other items bought on the instalment plan ...			-3	-2	-1	0	1	2	3
79. Took a cut in wage or salary without a demotion			-3	-2	-1	0	1	2	3

Question	From _____ to _____	From _____ to _____	Very nega- tive	Mode- rately nega- tive	Slightl y nega- tive	NO EF- FECT	Some what posi- tive	Mode- rately posi- tive	Extre- mely posi- tive
80. Suffered a financial loss or loss of property not related to work			-3	-2	-1	0	1	2	3
81. Went on welfare ..			-3	-2	-1	0	1	2	3
82. Went off welfare ..			-3	-2	-1	0	1	2	3
83. Got a substantial increase in wage or salary without a promotion			-3	-2	-1	0	1	2	3
84. Did not get an <i>unexpected</i> wage or salary increase ...			-3	-2	-1	0	1	2	3
85. Had financial improvement not related to work ...			-3	-2	-1	0	1	2	3
SOCIAL ACTIVITIES									
86. Increased church or synagogue, club, neighbourhood, or other organisational activities			-3	-2	-1	0	1	2	3
87. Took a vacation ..			-3	-2	-1	0	1	2	3
88. Was not able to take a <i>planned</i> vacation			-3	-2	-1	0	1	2	3
89. Took up a new hobby, sport, craft, or recreational activity			-3	-2	-1	0	1	2	3
90. Dropped a hobby, sport, craft, or recreational activity			-3	-2	-1	0	1	2	3
91. Acquired a pet			-3	-2	-1	0	1	2	3
92. Pet died			-3	-2	-1	0	1	2	3

Question	From _____ to _____	From _____ to _____	Very nega- tive	Mode- rately nega- tive	Slightl y nega- tive	NO EF- FECT	Some what posi- tive	Mode- rately posi- tive	Extre- mely posi- tive
93. Made new friends .			-3	-2	-1	0	1	2	3
94. Broke up with a friend			-3	-2	-1	0	1	2	3
95. Close friend died ..			-3	-2	-1	0	1	2	3
MISCELLANEOUS									
96. Entered the Armed Services			-3	-2	-1	0	1	2	3
97. Left the Armed Services			-3	-2	-1	0	1	2	3
98. Took a trip other than a vacation ...			-3	-2	-1	0	1	2	3
HEALTH									
99. Physical health improved			-3	-2	-1	0	1	2	3
100. Physical illness ...			-3	-2	-1	0	1	2	3
101. Injury			-3	-2	-1	0	1	2	3
102. Unable to get treatment for an illness or injury ...			-3	-2	-1	0	1	2	3
103.			-3	-2	-1	0	1	2	3

APPENDIX E

Hi,

My name is Nicholas Challis and 5 years ago I was diagnosed with non-Hodgkins lymphoma. It has been in permanent remission now for 2 years.

My specialist in Cape Town at Groote Schuur Hospital said I could continue with my studies in October 1996. I am doing a Masters degree in Research Psychology at Unisa.

I would like you to help me in a research project by volunteering to join a support group of fellow cancer patients who meet every two weeks here to discuss any problems you might be experiencing. Everything discussed is totally confidential within the group.

If you would like to take part, please tell your specialist who will arrange for us to meet here.

Sincerely

Nicholas

APPENDIX F

Hallo

My naam is Nicholas Challis. Ek is 5 jaar gelede gediagnoseer as 'n nie-Hodgkins lymphoma-pasiënt, maar is reeds die afgelope 2 jaar in remissie.

My dokter in die Groote Schuur Hospitaal (Kaapstad) het my toestemming verleen om voort te gaan met my studies gedurende Oktober 1996. Ek is tans besig met my Meestersgraad in Navorsingsielkunde aan Unisa.

Ek beoog om 'n ondersteuningsgroep bestaande uit medekankerpasiënte te begin. Hierdie groep sal tweewekliks vergader om enige probleme te bespreek. Alle inligting sal as streng vertroulik beskou word binne die groep. Sal u asseblief u dokter meedeel indien u sou belangstel om deel te neem aan hierdie projek sodat hy namens u kan reël om my te ontmoet?

By voorbaat dankie vir u samewerking.

Nicholas

APPENDIX G

HOW WAS TODAY'S MEETING? (TICK ONE)



WHAT I LEARNT WAS

.....

.....

WHAT I ENJOYED MOST WAS

.....

.....

WHAT I DID NOT LIKE WAS

.....

.....

I SUGGEST

.....

.....

HOW OFTEN DO YOU CONTACT OTHER GROUP MEMBERS ?

.....

APPENDIX H

DO YOU THINK THAT THE PATIENTS WHO ARE ATTENDING THE SUPPORT GROUPS HERE, ARE COPING WITH THEIR CANCER BETTER THAN THOSE WHO ARE NOT?

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.....

.....

SUGGESTIONS:

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